

THE MEANING OF THE CLIENT EXPERIENCE
AT A HEALTH CENTRE
WITHIN A FIRST NATIONS COMMUNITY
IN SOUTHERN ONTARIO

By

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**The Meaning of the Client Experience at a Health Centre
Within a First Nations Community in Southern Ontario**

Abstract

The purpose of this qualitative, interpretive study was to gain an understanding of the client experience at a health promotion and illness/injury prevention health centre within a First Nations community in Southern Ontario. A Heideggerian, hermeneutic approach and participatory processes were used within the research framework. Data were collected through the use of face-to-face, semi-structured interviews with 7 female and 5 male members of a First Nations community. Thematic analysis based upon the work of Max van Manen was employed and resulted in three overriding themes: (a) health and being healthy, (b) I use the health centre, and (c) I don't use the health centre. The first theme yielded a wholistic First Nations view of health that was grounded in traditional concepts of the medicine wheel in which health is achieved through balance in mind, body and spirit and emotion. Other essential components of being healthy included having choices and being able to make them, being able to care for self and others and eating right. The second theme revealed participants' views of their health centre as a valued source of information and services for both health and illness and as a trusted location for accessing traditional healers. Under the third theme, participants who reported little or no use of their health centre cited a number of reasons including: a) a lack of awareness of services offered, b) a lack of comfort and familiarity with the health centre's staff, services and building structure, c) a reliance on self-healing methods, and d) a reliance on other sources of health information such as family, community Elders,

the Internet and mainstream health care providers located outside of the community. The study provided insights on a First Nations community vision of an ideal health centre.

Implications for nursing education, research and policy are provided.

Key words: Aboriginal, First Nations, client experience, phenomenology, health services

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Chapter 1

Introduction

Statement of the Problem

Indigenous peoples are recognized as vulnerable populations in Canada, in part due to their experience of significant health status disparities and diminished access to health services as compared with other populations (Wilson & Young, 2008). Indigenous peoples experience a higher rate of illnesses, disabilities and premature death as compared with non-Indigenous Canadians (Smylie, 2009). In the past, research trends have focused more upon the quantification of rates of illness and mortality among First Nations, Inuit and Métis peoples in Canada, rather than upon the underlying social inequities (Richmond & Ross, 2009; Wilson & Young, 2008; Young, 2003). Social determinants of health such as poverty, poor employment options, low access to community resources and a lack of healthy food options negatively impact upon the health of Indigenous peoples in Canada (Adelson, 2005; Smylie, 2009).

In spite of the health disparities and social inequities faced by Indigenous peoples in Canada, mainstream health care providers often have little understanding regarding these issues and the unique life contexts within which Indigenous peoples experience health and illness. In response, the Society of Obstetricians and Gynecologists of Canada (SOGC), with input from many Indigenous and non-Indigenous contributors from health and social service arenas, published a detailed series of policy statements to inform clinical practice for health care providers. The series provided clinicians with comprehensive information and recommendations in relation to the health status (Smylie,

2000a), cross cultural care needs (Smylie, 2001) and the sociocultural life contexts (Smylie, 2000b) of Indigenous peoples in Canada. It was one of the first mainstream publications that was designed to inform health care professionals about the importance of understanding the connections between current Indigenous health issues and historical European confiscation of traditional Indigenous lands, subjugation of its peoples, and the oppression of their traditional ways of knowing and being. While a small number of publications such as the SOGC documents have been published over the years, their content is often written by, and from the worldview of the health care provider while little attention has been paid to the voiced experiences of Indigenous clients.

More recently, a small number of published research studies in North America have examined Indigenous client experiences in relation to mainstream (Western) health care settings such as hospitals (e.g.: Baker & Daigle, 2000; Browne, 2007; Guadagnolo et al., 2009) and urban health clinics (e.g.: Bucharski, Reutter, & Olgilvie, 2006). However, little is known about the experiences of First Nations peoples who are the recipients of care at health centres located within their First Nations communities or reserves. Even fewer studies have focused specifically on client perspectives and their experiences of First Nations health centres where the service mandate primarily addresses health promotion and illness and injury prevention. While many people of First Nations heritage live in urban areas, many of those who reside within their home reserves rely to some extent on the health services provided within their own communities to meet their health care needs. It is therefore important for both First Nations and non-First Nations health care providers to gain an understanding of the meaning that First Nations clients assign to

their experiences of reserve-based health services. This knowledge may assist health care providers in understanding why First Nations peoples use or avoid using health care services that are provided within their communities and may shed light upon their preferences in regard to health services utilization.

Terminology

Inherent in the scholarly pursuit of knowledge concerning the Indigenous peoples of Canada, researchers are required to navigate through a unique literary landscape which may present many terms with which they are unfamiliar. For the sake of clarity within this introductory chapter, the terms *Aboriginal*, *Indigenous*, *First Nation(s)*, *client* and *health centre* will be briefly defined in text. A brief glossary of terms (Appendix A) has been included that provides definitions of selected key terms that are not defined within text. Such terms will be written in italics font the first time that they appear in text with a glossary notation in brackets.

The term ‘Aboriginal’ comes from the Latin root word ‘Aborigine’ which means “from the beginning” (McMillan & Yellowhorn, 2004, p. 3). It refers to the descendants of the first peoples who occupied North America (Aboriginal Affairs and Northern Development Canada, 2010). The Canadian Constitutional Act (1982), decreed that the Aboriginal peoples of Canada include three distinct Indigenous peoples (First Nations, Inuit and Métis). The term “Aboriginal” provides Aboriginal peoples in Canada with a “unique status” that sets them apart from non-Aboriginal Canadians and those with other ethnic and racial ties (Warry, 2007, p. 10).

The term ‘Indigenous’ (as in Indigenous peoples) emerged in the academic literature in the 1970s coinciding with the political activism associated with the National Indian Brotherhood in Canada and the American Indian Movement. It may be used to link groups of people from around the world that have been subjected to *colonization* (refer to Appendix A - Glossary) by dominant cultures (Smith, 1999) and/or by a people’s spiritual and/or cultural ties to a particular geographic area (Warry, 2007). I will use the terms Aboriginal and Indigenous interchangeably in my dissertation.

The term ‘First Nation(s)’ became a commonly used term in the 1970s as a substitute for the older term *Indian* (refer to Appendix A – Glossary) which is no longer a term of choice among many peoples of First Nations heritages. ‘First Nation(s)’ generally refers to individuals who are considered under *The Indian Act* (Government of Canada, 1876) as *Status* or *non-Status Indians* (refer to Appendix A – Glossary). The ‘First Nation(s)’ term is also used by some groups of Indian peoples to replace the term ‘band’ in the formal names of their communities (Aboriginal Affairs and Northern Development Canada, 2010).

The term ‘client’ shall be used to identify all members of a First Nations community who represent the target population for services offered by health-mandated organizations such as *on-reserve* (refer to Appendix A – Glossary) health centres. The term ‘health centre’ shall be used primarily to refer to the community-based service provider within the researched First Nations community that addresses health service mandates that are (primarily) focused upon the areas of health promotion and illness/injury prevention activities. The client target population of the health centre

includes community band members and those eligible for band membership of all ages within the First Nations community of focus.

An emerging trend toward the “revitalization of the cultural values of Indigenous peoples” is directly tied to the “reclaiming” and use of traditional languages and stories (Ten Fingers, 2005, pp. S61-S62). In demonstrating respect for the First Nations community within which this study was conducted, I obtained the approval and ongoing linguistic guidance of its members to include where appropriate, Ojibwe language (*Anishinaabemowin*) translations of selected text within the dissertation. Where Ojibwe terms are used, they will appear in bracketed, italics font, paired with the English language equivalent.

Purpose of the Study

The purpose of the study was to gain an understanding of the meaning of the client experience at a health centre within a First Nations community in southern Ontario with a primary health service mandate focusing on health promotion and illness/injury prevention.

Summary

Historical trends in research concerning Indigenous peoples in Canada have primarily provided knowledge regarding the disproportionate experiences of diseases and premature death as compared with non-Indigenous populations. More recently, the health care literature has called for greater exploration and understanding of the linkages between Indigenous health disparities, the legacy of *colonialism* (refer to the Appendix – Glossary) and the broader contexts within which Indigenous lives are experienced. With

respect to First Nations communities across Canada, health care providers require knowledge concerning the ways in which health and health services are perceived and experienced. While a small number of studies have been published concerning First Nations client experiences of mainstream (Western) hospital and clinic settings in urban centres (Baker & Daigle, 2000; Barr & Wanat, 2005; Browne, 1995, 2007; Browne, Fiske, & Thomas, 2000; Bucharski, Reutter, & Ogilvie, 2006; Dodgson & Struthers, 2005; Garwick, Jennings, & Theisen, 2002; Guadagnolo et al., 2009; Kurtz, Nyberg, Van Den Tillaart, Mills, & Okanagan Urban Aboriginal Health Research Collective, 2008; Malach & Segel, 1990; Poudrier & Thomas Mac-Lean, 2009; Salvalaggio, Kelly, & Minore, 2003; Towle, Godolphin, & Alexander, 2006), little is known about their experience of services provided by on-reserve health centres. It is important for health care providers (of both First Nations and non-First Nations heritages) to gain a solid understanding of First Nations client perceptions and experiences of currently available, reserve-based health promotion and illness and injury prevention programs, in order to encourage appropriate health service utilization and ultimately promote positive health outcomes among First Nations populations.

This thesis is organized in the following manner. Chapter One introduces the problem and provides a brief discussion of the justification for the study. Chapter Two provides a brief overview of recent trends in First Nations health policy, service provision and research, followed by a critical review of the relevant literature. This literature review will address the historical context of First Nations Health Care in Canada over the last few decades and will address what is known about First Nations' perspectives and

client experiences of health services in Canada and the United States. Chapter Three provides a discussion of the philosophical and methodological foundations upon which the study was designed. I explain why I chose a Heideggerian, hermeneutic design and how this approach is culturally congruent with Indigenous knowledge systems and Indigenous research methodologies. I address my choice to incorporate participatory processes into my research design. Chapter Four provides a description of the evolution of my stance as the researcher and participant in this study. Chapter Five provides a description of my research method and my integration of the work of Max van Manen. Chapter Six presents four themes of the client experience that emerged from my data analysis and the ways in which the themes connect to Heidegger's existential elements of corporeality, relationality, spatiality and temporality. Chapter Seven provides recommendations for change in First Nations health services provision based upon the findings of the study and proposes implications for nursing practice, education, research and policy. Chapter Seven also includes a summary of recommendations that were proposed by participants in relation to their collective vision of an ideal health centre within their First Nations community.

Chapter 2

Critical Review of Relevant Literature

In this chapter, I will begin with a brief overview of trends in First Nations health policy, and service provision and the role that research on First Nations health issues has played in informing these concepts over the last few decades. I will then discuss the findings that resulted from my critical review of relevant research literature concerning First Nations client experiences with health services. I will outline my literature review strategy and will discuss the literature review findings under three overarching themes that include: (a) being respected and understood; (b) being comfortable; and (c) being in control. I will conclude by summarizing the overall research findings and gaps in the literature concerning the First Nations client experience.

Recent Trends in First Nations Health Policy, Services and Research

Early in my doctoral studies, I learned how important it was to gain an understanding of the complexity and interrelationships among the concepts of First Nations health policy, health service delivery, and First Nations health research. The largely Federally-based health service funding sources and methods of allocation for First Nations vary substantially from the way in which health services are funded and delivered to non-Indigenous populations in Canada. The content in this section provides a basic context within which to situate a brief analysis of First Nations health service delivery and its relationships with evolving First Nations health care policy and research agendas.

First Nations health policy and service provision. In 1876, Canada passed the *Indian Act* (Government of Canada, 1876) that set forth the Federal Government's obligations concerning Aboriginal peoples in Canada. Specific to First Nations, the *Indian Act* regulated the management of First Nations reserves, including the provision of health care. This act is still used today but has had several revisions (Royal Commission on Aboriginal Peoples, 1996). The Federal Government used the *Indian Act* to limit its responsibility for the health care of First Nations only to those identified under the *Indian Act* as Status Indians who live on reserves (Kelly, 2011).

In the late 1800s, following the establishment of the Indian Act, an Indian agent system was formally established on First Nations reserves. Indian agents were assigned legislative powers to carry out federal policies that were largely designed to 'civilize the Indian' through assimilation. The Indian agent's powers included responsibility for overseeing the provision of limited medical services to First Nations populations. Few were qualified medical doctors and most only had a lay knowledge of health service provision. The on-reserve availability of medical services was limited in scope and sporadic in nature and was provided by a limited number of federally employed medical doctors, missionaries and fur traders (Waldram, Herring, & Young, 2006).

Limited efforts to coordinate First Nations on-reserve health care at the national level were not initiated until the early 1900s (Young, 1984). In the 1920s, the high prevalence of tuberculosis on many reserves, along with pressure from non-First Nations Canadians living in close proximity to reserves, led to the initial formalization of health services on selected reserves. The first on-reserve nursing station was established in the

1930s in Manitoba and others followed soon after (Waldram, et al., 2006). Health promotion and prevention services were then mostly provided by nurses using translators. Early in the 1970s, *Community Health Representatives* (see Appendix A – Glossary) and substance abuse counsellors were added to assist First Nations communities to address their basic needs in dealing with illnesses, maternal-child health and immunization. In spite of the provision of these basic services, rates of immunization were low and deaths associated with infectious diseases were common. Respecting the diversity of First Nations reserves across Canada, the quality and extent of the on-reserve health service provision would have depended upon the population size and geographic location (Lavoie & Williams, 2009). Similar accounts of limited on-reserve health service availability as described in the paragraphs above were relayed to me by community members from the First Nations community in which my doctoral study took place. They often spoke of a non-First Nations nurse who provided services for many years within the community and could be seen regularly as she travelled around the community by bicycle.

Despite legislated government obligations set out in the *Indian Act* and the subsequent provision of health services on behalf of Aboriginal peoples, it has been well established in the literature that Aboriginal peoples have known, and continue to experience a far greater number of health disparities as compared with other population groups in Canada (Adelson, 2005; Newbold, 1998; Young, 2003). The health disparities or “relative disproportionate burden of disease” (Adelson, 2005, p. S45) faced by First Nations and Inuit populations in Canada was the focus of the *Study of Health Services*

For Canadian Indians (1969) by the Booz•Allen and Hamilton Ltd consulting firm.

Their findings led the Federal Government to develop the Federal Indian Health Policy in 1979 (Kulig, MacLeod, & Lavoie, 2007). The goal of the Federal Government's health policy revision in this area was to raise the health status of First Nations populations and to provide them with opportunities to take greater control over the health services that they received within their own communities (Health Canada, 2007).

In 1989, Health Canada enacted the Health Transfer Policy to further promote the transfer of health services control to First Nations and Inuit communities in Canada (Wigmore & Conn, 2003). While the 1989 Health Transfer Policy addressed both First Nations and Inuit communities, I will confine my discussion of this topic to the transfer of health service control from the First Nations and Inuit Branch (FNIHB) of Health Canada to First Nations communities south of the 60th parallel (Health Canada, 2004). Inherent in the establishment of the Health Transfer Policy was the Federal Government's intent that First Nations' gradual assumption of control over the delivery of health services in their communities would evolve slowly, in stages as they developed the internal administrative skills and resources to do so.

The health transfer process. The methods used to transfer the responsibility for, and the control of health services from the FNIHB to First Nations communities varied by community (Lemchuk-Favel & Jock, 2004). Inherent in the initial objectives of the health transfer process was the intention to provide each community with choice and flexibility. In the first handbook health transfer guide published by Health Canada in 1999 and revised in 2004, it outlined three approaches for the transfer of health service

programs and services that included “Health Services Transfer, Integrated Community-Based Health Services, and Self-Government” (Health Canada, 2004, p. 1). For a brief summary of these approaches, refer to Appendix A – Glossary.

Linked to the potential success of First Nations health transfer initiatives was the incorporation of familiar, culturally-appropriate, “indigenous ways of knowing and understanding health and healing” (Smylie & Anderson, 2006, p. 604). Further, under the *Canada Constitution Act* (1982), First Nations as Aboriginal peoples have the right to generate and transfer knowledge that accurately represents their unique identities. They have the right to ensure that First Nations focused health research initiatives seek to investigate issues that are of value and importance to them. This includes the health determinants that are identified by, and specifically address Aboriginal populations in Canada. The gradual assumption of control of health services, social services and education by First Nations communities can be viewed within the broader process of increasing self-determination among Indigenous populations groups in Canada (Waldram, et al., 2006).

Ten years after the initiation of the health transfer process, Health Canada (1999) completed an evaluation of its progress to date. Health Canada’s evaluative document titled: *Ten Years of Health Transfer First Nation and Inuit Control* reported that by 1999, close to 80% of eligible First Nations and Inuit communities were engaged at some level within the health transfer process. Challenges cited by Health Canada concerning the health transfer process included the need to address the health requirements of a rapidly growing Aboriginal population in Canada, as well as issues of accountability and

sustainability of health services by both the government and Aboriginal communities.

The report included a lengthy, chronological list of its achievements which largely focused upon the number of signed health transfer agreements completed between 1989 and 1999, and mentioned the release of a number of publications including multiple documents to guide communities in the transfer process.

Contrary to Health Canada's 1999 summary report of its achievements in the first ten years of overseeing the health transfer process, a number of parallel reports (Jacklin & Warry, 2004; Smith & Lavoie, 2008) were published within the academic sector which painted a less favourable picture. While a detailed discussion of recent evaluations of the health transfer process is beyond the scope of this dissertation, the following summary outlines some of the critical issues concerning the health transfer process which remain largely unresolved.

The health transfer relationship between the Federal Government and each First Nations community is renegotiated every year (as with contribution agreements), or every three to five years, depending on the type of funding transfer process agreement. Funding of health services since the inception of the health transfer process has not kept pace with population growth in First Nations communities. While the promotion of 'self-determination' in the form of greater local decision making concerning health services in First Nations communities was stated as a central component of Canada's Health Transfer Policy, control of First Nations health services still remains largely top-down with little government address to the unique health needs and preferences of each First Nations community (Jacklin & Warry, 2004).

In a 2008 review of the health transfer process, Smith and Lavoie (2008) echoed the comments of Jacklin and Warry (2004) concerning the fact that funding of health transfer agreements is not keeping pace with changes in community demographics. In particular, Smith and Lavoie (2008) noted that some funding caps that were negotiated at the time of the establishment of initial agreements in a number of communities have not been removed and thus hamper the ability of communities to compete for scarce human resources against the higher health care provider salaries and benefits offered by unionized government employers off reserves.

Smith and Lavoie (2008) noted that in recent years, the First Nations and Inuit Branch of Health Canada has initiated new ‘mandatory programs’ through the health transfer process that do not integrate well with local community health care plans, service needs and preferences, and that the establishment of such program mandates involved a lack of consultation with First Nations communities. Participants in the study by Smith and Lavoie (2008) viewed the health transfer process as inflexible and not supportive of local community needs for wholistic mental health services that were comprehensive, sustainable and culturally congruent.

The literature generally supports the notion that the health transfer process has benefitted First Nations communities in terms of bringing greater leadership and administrative expertise concerning health services to First Nations communities (Smith & Lavoie, 2008; Waldram, et al., 2006). However, while Aboriginal peoples in Canada have assumed greater local autonomy in some aspects of health care decision-making since the inception of the health transfer process, their overall health status has declined

in the same time period (Kelly, 2011; Warry, 2007). This may be in part due to an expected lag in time between the implementation of the policy and the time in which each First Nations community can begin to show measurable health benefits (Warry). Communities continue to experience many challenges in administering their health transfer agreements. Jacklin and Warry (2004) concluded that if the Canada's health transfer policy is to become an effective solution for the health issues faced by Indigenous peoples in Canada, it merits the Canadian Government's address to "better planning and consultation, collaborative policy making, and improved financing" (p. 230). Research can play an important role in the monitoring and evaluation of First Nations perspectives of the health transfer process at the local community level. It is interesting to note that in a 2010 study conducted by Lavoie, Forget, Prakash, Dahl, Martens and O'Neil, communities in Manitoba that entered into a transfer agreement demonstrated superior health outcomes as compared with other communities that elected to use an integrated community-based health services approach.

One community leader from the community within which my doctoral study was conducted stated to me that the health transfer process officially promotes a message of gradual assumption of control of health services by First Nations communities, but that little has changed since the community's signing of the first contribution agreement except for a significant increase in the time required for the frequent submission of copious numbers of detailed administrative reports to the Federal Government. I have heard the term "cookie cutter" and "standardized" used by community members to describe such government programs which they stated show little regard or tolerance for

community requests for health service programming which falls outside of the vision of the First Nations and Inuit Branch of Health Canada.

First Nations health research. Both qualitative and quantitative research approaches have been employed for many years to collect data concerning the health issues and health service delivery in relation to Aboriginal populations in Canada. In particular, quantitative research studies employing the use of surveys have been actively used by the Canadian government, academic researchers and health organizations since the mid-1900s for this purpose. An example of such a study includes the *First Nations Regional Longitudinal Health Survey RHS 2002/03 (Assembly of First Nations/First Nations Information Governance Committee, 2007)* and the *RHS Phase 2 (2008/10)(First Nations Information Governance Centre, 2011)*. According to Dr. Janet Smylie, a noted Aboriginal physician and researcher in Canada, the RHS is considered the most comprehensive study of First Nations health and living conditions in Canada (2009). Other quantitative studies focusing on health assessment of Indigenous peoples in Canada have relied on four other primary sources of data including census data, vital registration statistics, data on service utilization and health *surveillance* (refer to Appendix A – Glossary) systems (Smylie & Anderson, 2006).

While quantitative studies have contributed to the body of scientific knowledge concerning health status, diseases, socioeconomic inequities, health seeking behaviours and related issues associated with Aboriginal peoples in Canada, Smylie and Anderson (2006) cautioned users that the quality of such studies may be suspect, and may not include adequate coverage of the First Nations, Métis and Inuit peoples that such studies

claim to represent. “The major coverage challenge is a lack of accurate identification that respectfully, systematically, comprehensively and consistently recognizes self-identified First Nations, Métis or Inuit ethnicity” (p. 603), while challenges to quality primarily result from the use of substandard data sources, suspect research methodologies, or both.

In 2003, T. K. Young, a noted Canadian health epidemiologist, completed an intensive review of health research completed on Aboriginal groups in Canada. He concluded that the majority of research studies on Aboriginal peoples’ health that had been completed since the 1970s were concerned mostly with population-based, quantitative investigations associated with the causes and control of communicable diseases such as tuberculosis, as well as the study of diabetes and suicide.

Specific to health research on First Nations populations in Canada, Wilson and Rosenberg (2002) noted that a large body of quantitative research literature existed which was largely epidemiological in nature and examined health and illness in relation to health determinants. They concluded however that there existed a significant body of qualitative research on First Nations health that made linkages between culture and health. As will be demonstrated in this literature review, there has been an upsurge in recent years in the use of qualitative research (e.g.: Browne, 2007; Dodgson & Struthers, 2005; Salvalaggio, Kelly & Minore, 2003) to yield a greater understanding of the Indigenous experience of health and illness as it is rooted within the broader historical, social, economic, political, cultural and linguistic contexts of life.

Marlene Brant Castellano (2004) contended that regardless of the research methodology employed, research initiatives have often been viewed negatively by

Aboriginal peoples, given that the research aims and reported outcomes were often erroneous and detrimental. Castellano further stated that there is a deliberate movement among academia, government and indigenous communities to transform the use of Aboriginal research from an agent of stigmatization and colonization, to a tool that more accurately represents Aboriginal peoples and their world views. The success of these aims depends upon the use of research methodologies that are congruent with, and respectful of Indigenous ways of generating and translating knowledge for use by Aboriginal peoples (Kovach, 2009; Smith, 1999). My address to the relevant topics of Indigenous knowledge systems, knowledge translation, Indigenous methodologies and participatory processes can be found in Chapter 3 within my discussion of the philosophical and methodological foundations of the current study and my application of this knowledge can be found in Chapter 5 within the discussion of my method.

Search Strategy

The literature review included all English language publications that addressed the client experience with health care services from the perspectives of First Nations, Métis, and American Indian populations within Canada and the United States. Studies related to the client experiences of Inuit peoples who live north of the 60th latitude were excluded from the literature review because of their relative geographic isolation and the differences in government health care policies and methods of health service delivery for Inuit populations, as compared to other Indigenous populations in North America. I limited my critical review of the scholarly literature to a variety of sources that were published from 1990 to 2012. This timeframe reflects the earliest establishment of

federally-funded health centres (under the health transfer process) within First Nations communities in Canada. It also coincides with the establishment of the Aboriginal Healing Foundation in Canada that provided funding for health and social service projects in Aboriginal communities to address the individual, familial and broader societal legacy of sexual and physical abuse experienced by Aboriginal peoples as a result of the Indian residential school system (Aboriginal Healing Foundation, 2002) .

A small number of studies were found that described varied Aboriginal peoples' client experiences of health service delivery within North America. However, a significant proportion of these studies described the client experience from the exclusive perspective of Indigenous or non-Indigenous health care providers. For the purposes of this literature review, a study was therefore considered as relevant for inclusion, only if the study included data concerning client experiences as expressed by the clients themselves. The electronic databases that were used during this doctoral study included: Bibliographic of Native North Americans, CINAHL, First Nations Periodical Index, Health & Wellness Resource Centre, Medline, Ovid Nursing, ProQuest Nursing & Allied Health Source, PsychInfo, PubMed Central Canada, and Scholars Portal (including E-Journals @ Scholars Portal). Refer to Appendix B - Literature Review Key Terms and Search Strategy for a detailed list of key search terms, scholarly databases, Internet sites and related resources that were used to conduct the literature review.

I found 14 published studies that met the inclusion criteria (Baker & Daigle, 2000; Barr & Wanat, 2005; Browne, 1995, 2007; Browne, Fiske, & Thomas, 2000; Bucharski, Reutter, & Ogilvie, 2006; Dodgson & Struthers, 2005; Garwick, Jennings, & Theisen,

2002; Guadagnolo et al, 2009; Kurtz, Nyberg, Van Den Tillaart, Mills, & Okanagan Urban Aboriginal Health Research Collective, 2008; Malach & Segel, 1990; Poudrier & Thomas Mac-Lean, 2009; Salvalaggio, Kelly, & Minore, 2003; Towle, Godolphin, & Alexander, 2006). All of the studies were published in peer reviewed journals. Nine studies took place in Canada, four were carried out in the United States (US) and one took place in both Canadian and US research settings. Among the 14 studies, 12 used a qualitative method, one employed a quantitative method and one study used a mix of both quantitative and qualitative methods.

All 14 studies included data that addressed client accounts of health care interactions with multiple health care provider types (both licenced and unlicensed staff). Therefore, for the sake of clarity in this discussion, the use of the generic phrases *health care provider* and *health care worker* will be used interchangeably to refer collectively to both licenced and unlicensed health care personnel who are employed within the health care system. Only two of the selected studies restricted the focus of their research questions to clients' health care interactions with a specific health care occupation; Browne (2007) aimed to study client interactions with nurses, while Towle et al. (2006) focused primarily on physician-client interactions. When discussing individual study findings, occupational roles will be named only if specifically addressed in the research.

Appraisal of study rigor. The evaluative guidelines by DiCenso, Guyatt and Ciliska (2005) were used to appraise the rigor of relevant quantitative research literature. The guidelines established by Russell and Gregory (2003) were used to evaluate the rigor of relevant qualitative studies. The criteria developed by Meleis (1996) for the appraisal

of rigor in cross-cultural research were also used, given the cross-cultural nature of many Aboriginal-focused studies (through the involvement of Aboriginal participants and a predominance of non-Aboriginal research investigators).

Refer to Appendix C - Table Summary of the Critical Review of the Relevant Literature for a summary of each of the 14 selected research studies that to some extent, addressed Indigenous participant perspectives of the ‘client experience’ in relation to health care. Appendix C includes a brief description of the purpose, method and main study findings of each relevant study, as well as a brief assessment of the associated strengths and limitations of each study, based upon the above-mentioned evaluative guidelines and criteria.

The Client Experience: Themes in the Literature

In this section, I will provide a discussion of the relevant findings drawn from the literature that address the meaning of the client experience in relation to health care and the health care system under three overarching themes that include: (a) being respected and understood; (b) being comfortable; and (c) being in control.

Being respected and understood. The degree to which many Indigenous clients feel respected by health care providers often influences clients’ perceptions of clinicians as trustworthy or untrustworthy. Browne (1995) conducted a qualitative, ethnographic study within a Cree-Ojibway community in northern Manitoba where she explored the meaning of respect from the perspective of community members during clinical interactions with Western health care providers. Being respected for many clients in this study meant that they felt as if they were viewed by health care workers as unique,

worthy and as equals. Among her findings, Browne (1995) concluded that for First Nations clients, respect was often viewed as a “reciprocal process” (p. 101) in that clients were more likely to respect and trust health care workers when they felt respected by them in clinical interactions. This finding was reflected in two other studies by Poudrier and Thomas Mac-Lean (2009) and Towle, et al. (2006). Similarly, clients who perceived a lack of respect from health care providers were more likely to feel demeaned, or to have feelings of inferiority in relation to their health care providers (Baker & Daigle, 2000; Browne, 1995). A subsequent ethnographic study by Browne (2007) examined clinical encounters between First Nations women and nurses in a Western Canadian hospital setting. Browne’s (2007) findings revealed that nurses’ beliefs about Aboriginal peoples directly influenced their attitudes and behaviours toward clients, as well as clients’ perspectives of the quality of care received.

A common theme expressed in the research literature (Browne, 1995; Browne, Fiske & Thomas, 2000; Browne & Fiske, 2001) paired clients’ perceptions of being respected by health care providers with their stated experiences of being listened to genuinely and attentively. Health care providers’ conveyance of a genuine demeanour was viewed by many clients as a sign of respect and increased the clients’ valuing of, and comfort within the provider-client relationship. Being respectful included workers’ genuine efforts to listen attentively in order to gain an understanding of clients’ unique life situations and to communicate interest in, and appropriate address to clients’ personal values, beliefs and practices in relation to health and health care.

In one qualitative descriptive study by Towle et al. (2006) that examined communication between doctors and clients in an Aboriginal community, the researchers reported that clients' negative experiences were influenced by what they observed in the physicians' verbal and non-verbal communication. For example, doctors that used medical lingo were perceived as using their professional status as a way to distance themselves from clients. Towle et al. noted that a physician's subtle and/or overt conveyance of position and authority in both verbal and non-verbal behaviours led some clients to report feeling distrustful and at risk of personal harm. By contrast, a physician who appeared 'down to earth', genuine, and who took the time to learn about the client's culture and interests, was more likely to be trusted. Clients paid close attention to the more subtle, non-verbal behaviours exhibited by physicians such as tone of voice, and total time they spent with patients.

A number of studies were found that echoed the findings of Towle et al. (2006) regarding Indigenous client observations of health care providers' use of time and conveyance of genuineness in the health care encounter (Barr & Wanat, 2005; Dodgson & Struthers, 2005; Malach & Segel, 1990). For example, clients' diminished perceptions of being respected and understood occurred when health care workers appeared hurried and communicated in an abrupt manner (Barr & Wanat; Dodgson & Struthers). Malach and Segel (1990) studied the perspectives and experiences of American Indian families in New Mexico concerning health care services rendered on behalf of their children with special needs. In addition to client/family caregivers' observations that doctors often

appeared hurried, many reported that they were not allowed adequate time to talk about their children's health issues or to ask important questions.

A Canadian, qualitative study of urban Aboriginal women's experiences of health care (Kurtz et al., 2008) reported similar findings in that the Aboriginal female clients felt that they were not provided adequate time to discuss their concerns and symptoms with their physicians. Within the literature, health care providers' behaviours that were labelled as hurried and disrespectful of Indigenous clients were often associated with clients' perceptions of dismissal or trivialization of their symptoms and/or their related questions and concerns (Browne, et al., 2000; Kurtz, et al., 2008) and being cut off in conversation (Browne, 1995; Malach & Segel, 1990).

Even when health care providers conveyed genuineness in their approach, listened attentively and provided adequate time to meet with clients, this did not necessarily assure clients that their voices had been fully heard, or that they 'felt' understood, or had 'been' understood. The experience of not feeling or not being understood and/or being misunderstood by health care providers were common sub-themes of clients' overall experiences of being disrespected by health care providers. Concerning physicians, Malach and Segel (1990) noted a common response among Indigenous parents of children with special needs as, "Doctors don't understand Indians and the way we do things, so we don't feel comfortable in dealing with them" (p. 223).

In a qualitative study, Baker and Daigle (2000) investigated how members of a Mi'kmaq First Nations community in New Brunswick described their client experiences associated with a recent hospitalization. A central finding of their research addressed

client perceptions of being misunderstood within the clinical interaction. The main source of misunderstanding was perceived by clients as resulting from the differing cultural perspectives and cross-cultural nature of the provider-client relationship. Nurses in the study often judged client behaviours based upon their assumptions (or misassumptions) about the client's cultural group affiliation. Such judgments were often made by nurses without consideration of the possible impact of factors in each client's unique life situation, such as poverty, the experience of family violence and/or the residential school system.

A number of studies documented Indigenous client experiences where health care workers provided care based upon a lack of understanding or misassumptions about the socioeconomic status of a client (Browne, et al., 2000; Bucharski, et al., 2006; Poudrier & Thomas Mac-Lean, 2009). In one study, health care workers demonstrated disregard for the personal circumstances of low income clients by assessing fines for clients who arrived late or missed appointments altogether (Browne, et al. 2000). Poudrier and Thomas Mac-Lean (2009) explored Aboriginal women's experiences of breast cancer, using photovoice in a Saskatchewan community. Some women in the study felt that their own lived experiences of breast cancer were not understood by health care providers. Information and advice provided by the health care workers and their clinical expectations of clients were often viewed as incongruent with the clients' lived, socio-economic conditions. A qualitative, descriptive study by Bucharski et al. (2006) addressed Aboriginal women's experiences of testing and counselling in relation to the Human Immunodeficiency Virus (HIV) in Western Canada. A major finding of their

study was that the extent to which health care providers recognized, understood and addressed the unique past and present life contexts of Indigenous clients, led to clients' experiences of a positively or negatively perceived health care encounter. Perhaps even more significant was the finding that Aboriginal clients' negatively perceived experiences of HIV testing and counselling as culturally incongruent, often resulted in clients' reluctance to share concerns and symptoms, and the likelihood that they would not return for further testing.

In addition to a lack of understanding of cross-cultural differences by health care providers, a number of studies reported client experiences where health care providers provided discriminatory care based upon racism and/or negative stereotyping (Baker & Daigle, 2000; Barr & Wanat, 2005; Browne, 1995, 2007; Bucharski, et al., 2006; Kurtz, et al., 2008; Poudrier & Thomas MacLean, 2009). A study by Kurtz et al. (2008) explored Aboriginal women's perspectives of health and social services provision in the Okanagan Valley of British Columbia. The researchers framed the client experience of racism as occurring "where the colour of their skin determined the type of treatment they received—the darker their skin, the worse their encounter or the more negative the assumptions made by health care providers" (p. 56). Kurtz et al. (2008) noted multiple references to negative stereotyping of clients by health care workers, based on ethnicity. For example, many women recalled in their stories, health care workers' assumptions of client alcohol and substance abuse, despite the fact that many of the participants reported no history of substance misuse. One woman recounted an experience where her overt

physical challenges resulting from a recent stroke were assumed by a health provider to be the result of alcohol consumption.

My literature review revealed that discriminatory care of Indigenous peoples that is based upon negative stereotyping can result from the beliefs of individual health care providers, and can stem from discriminatory policies and procedures that are embedded within the fabric of everyday routines of health care organizations. On an individual provider level, Browne (2007) cited an example where a nurse held negative stereotypical beliefs about Aboriginal peoples' as supposedly having an affinity for narcotic use and a predisposition for substance abuse. This formed the basis of the nurse's rationale for the withholding of post-operative pain medication from an Aboriginal woman who came from a remote First Nations reserve, despite the client's repeated requests. Similarly, Barr and Wanat (2005) studied how members of numerous, low-income, ethnic minorities experienced patient services within health care organizations in the United States. In regard to their health care encounters, American Indian participants voiced significant alarm about perceived experiences of negative stereotyping by some health care providers. Such stereotyping often manifested in the health care providers' automatic provision of health promotion advice and treatment offers related to obesity, nutrition, alcohol and drug use that were more associated with the providers' beliefs about the Indigenous cultural community and were not relevant to the specific needs and preferences of recipients as members of that population. Garwick, et al. (2002) studied American Indian family caregiver perceptions of health care services provided for their chronically ill children in Minneapolis. Approximately two-fifths of the family

participants felt that health care providers believed things about them that were not true and were based upon false, negative stereotypes. Indigenous caregivers stated that their indirect eye contact and quiet demeanour were often incorrectly interpreted by health care providers as disinterest, disrespect or a lack of education.

On a more systemic level, Browne and Fiske (2001) addressed the impact on Aboriginal women of negative stereotyping within the health care system; in particular, on women as mothers. The authors stated that this type of ethnic, gender and role discrimination is a direct outcome of historical colonization of Aboriginal peoples in Canada. They cited a particular example where an Aboriginal woman had consistently sought treatment for her infant's diaper rash with her family doctor. Despite her strict adherence to the family doctor's treatment recommendations, the baby's rash had worsened, thus requiring the mother to bring the baby to an urban hospital emergency room (ER). The night before her visit to the ER, the mother had sustained a black eye while playing baseball. Assumptions drawn by the ER health care team based upon the mother's bruised facial appearance and the baby's skin deterioration, led them to apprehend the child on the assumption that she was an unfit mother. A contact with the mother's family doctor would have yielded strong support for the women's mothering skills and devotion to her child, yet no such inquiry was made prior to the infant's apprehension. A study by Bucharski et al. (2006) referred to institutionalized discrimination involving HIV testing of Aboriginal women in Canada. Bucharski et al. (2006) noted that some Aboriginal women avoided seeking HIV testing during pregnancy

and/or if they had children based upon the fear of child apprehension in the event that an HIV positive result occurred and became known.

The literature provided multiple examples of client experiences in relation to respect received from, and understanding by health care providers. Overall, I was able to conclude that being respected included the client experiences of being treated as an equal, being listened to attentively by health care providers who conveyed a genuine demeanour, and being allowed adequate contact time for clients to express their concerns and ask questions. A perception of being respected was often directly associated with clients' likelihood of perceiving health care providers as trustworthy.

Additionally, the literature provided illustrations of a variety of circumstances that can leave Indigenous clients feeling not respected and not understood in health care interactions. Underlying sources of disrespect and misunderstanding can include health care providers' lack of cultural understanding, the provision of care that is incongruent with clients' life contexts and cultural affiliation, and the provision of care that is based upon racism and negative stereotyping. Equally important to consider however, are some of the documented, subsequent common life choices and health behaviours that have been noted in the literature as Indigenous clients' exhibited responses to such negatively perceived health care experiences.

An Indigenous client's mistrust of the health care provider and/or the health care system in which care is provided, may result in the client's reluctance to share health concerns and ask questions (Dodgeson & Struthers, 2005; Malach & Segel, 1990; Poudrier & Thomas Mac-Lean, 2009) and/or to avoid seeking health care services

altogether (Bucharski, et al., 2006). In a quantitative study by Guadagnolo et al. (2009), the perspectives of Native Americans were compared with those of non-Hispanic Whites concerning trust and mistrust of medical personnel in relation to cancer treatment. Approximately 21% of the Native Americans versus 5% of the non-Hispanic Whites delayed getting medical care due to their mistrust of physician and nursing personnel. Dodgson and Struthers (2005) further noted that clients who mistrusted their health care providers were often hesitant to share sensitive information.

Due to experiences of racism and stereotyping, Browne and Fiske (2001) reported women's accounts of feeling the need to alter their appearance and deportment in order to receive quality treatment. This often included dressing up and speaking in a certain way in order to appear 'educated'. The authors noted that these choices illustrated the women's assumptions that looking and sounding more sophisticated and/or educated provided them with "credibility and legitimacy as medical subjects", while also demonstrating the women's sense of "incredibility and inadequacy in the eyes of health professionals" (p. 135).

Another way in which clients transformed themselves during clinical encounters was documented by Poudrier and Thomas Mac-Lean (2009) and Baker and Daigle (2000) by not asking questions. In the study by Poudrier and Thomas Mac-Lean (2009), Aboriginal women diagnosed with breast cancer stated that they did not always comprehend what was being told to them or expected of them by health care personnel. Fearing that they would appear "unintelligent" (p. 315), many chose not to ask for clarification of instructions and advice. In spite of the insecurity felt by Mi'kmaq clients

that resulted from not knowing what to expect in the hospital setting, Baker and Daigle cited more culturally-grounded reasons why they chose not to ask questions of health care providers. Their reluctance to seek clarification of their informational needs in health care encounters was referred to by Baker and Daigle (2000) as “giving no trouble”. One Mi’kmaq client was recorded as stating, “Native people never ask for anything, they never complain, they take whatever the doctor or nurses give them. Our people are quiet and shy.” (p. 19). The authors of the study went on to say that this behaviour was in part, based upon a cultural norm where clients expected that the information they needed should be provided by health care providers without being requested.

Being comfortable. Among the 14 relevant research articles that were included in this literature review, a second overarching theme in relation to the health care encounter for Indigenous clients addressed the importance of experiencing an adequate level of personal comfort with both people/health care providers and the health care system’s overall structure and routines. Health care providers’ actions that contributed to the promotion of client comfort included , but were not limited to providing unexpected acts of kindness, genuine gestures of care and concern, and opportunities to establish long-term provider-client relationships (Browne & Fiske, 2001; Browne et al., 2000). With specific regard to clients’ expressed needs for access to stable provider relationships (especially with physicians), Browne et al. (2000) noted that satisfying relationships with health providers were often difficult to create and sustain in light of the relative high turnover of health care providers in rural and remote locations. Malach and Segel (1990) stated that clients frequently recounted stories of feeling uncomfortable and unfamiliar

with the experience of seeing different doctors at each clinic visit and not having access to health care specialists with whom they could build a sustained relationship. Other examples of health care provider gestures that promoted feelings of comfort and familiarity among Indigenous clients included allowance for large groups of family visitors in the hospital room (Baker & Daigle, 2000; Salvalaggio, et al., 2003), and overt recognition of clients' unique cultural needs, preferences and points of view (Browne, 1995; Browne & Fiske, 2001; Browne et al., 2000; Garwick et al., 2002).

From a system point of view, clients expressed higher levels of comfort when health care organizations respected their cultural beliefs by offering options for the incorporation of traditional medicines, healers and ceremonies within clients' treatment plans (Buharski et al., 2006; Dodgson & Struthers, 2005; Garwick et al., 2002). For example, in the study by Buharski et al. (2006), clients felt that the Indigenous cultural tradition of 'smudging' should be a culturally-congruent option with HIV testing services for Aboriginal women in the clinical setting.

Smudging is an Aboriginal cultural practice that involves the burning of dried grasses while saying a prayer. People may inhale or cup the smoke in their hands and spread it over different parts of their body as they pray. It is believed that when a person smudges, her prayers are carried to the Creator. Women in the study held various beliefs about what smudging was, how to smudge, and when to smudge; however, they agreed that culturally appropriate HIV testing should incorporate this option. (p.737)

Bucharski et al. (2006) noted that the presence of “friendly Aboriginal staff within the health centre” (p. 739) promoted enhancement of clients’ feelings of comfort and familiarity in part, due to a presumed mutual understanding, based upon shared experiences of being Aboriginal from a life context perspective.

While the literature did provide examples of both health care provider actions and broader health care system efforts that promoted a positive sense of comfort and familiarity among Indigenous clients as discussed above, the majority of relevant studies focused more upon clients’ negative experiences of vulnerability in health care relationships, particularly, within the Western or mainstream health care system. Vulnerability as experienced by Indigenous clients was most often linked in some way to perceived imbalances in power in the health care relationship and/or past or present experiences of colonization and discrimination. For some clients, especially women, exposure of the body for physical examinations or treatments was often associated with traumatic memories associated with residential school or demeaning health care experiences from the past (Brown & Fiske, 2000; Browne et al., 2000).

Bucharski et al. (2006) reported three key life experiences of Aboriginal women that may shape their perspectives of present-day encounters with mainstream services including: “childhood sexual abuse; discrimination; and inegalitarian intimate adult relationships” (p. 728). These findings point to the importance of recognizing the potential for each of these life experiences to generate both an altered sense of self, and others, and provide a cautious and fearful emotional lens through which some clients may approach and ultimately experience health care encounters. If nurses and other health care

providers do not understand (or take the time to learn about) the unique Indigenous contexts within which clients have lived their lives, there is the potential for the provider-client relationship to present further risk for harm through the reinforcement of past negative client experiences. Other client experiences that contributed to feeling vulnerable included, but were not limited to feeling abandoned and socially isolated (Bucharski et al, 2006; Salvalaggio et al., 2003); marginalized and alienated due to their need to live in two cultural worlds simultaneously (Dodgson & Struthers, 2005); and feeling like an intruder or stranger within the mainstream health care system (Browne & Fiske, 2001; Browne et al., 2000; Baker & Daigle, 2000).

With respect to abandonment and social isolation, female participants in the study by Bucharski et al. (2006) identified system-wide racial and ethnic discrimination as a central contributing factor to their feelings of isolation, which led them to be hesitant to access HIV testing services in the future. Vulnerability experienced through feelings of loneliness and social isolation were perpetuated in situations where Indigenous peoples were separated from familiar environments, family and friends, as noted in the study by Salvalaggio et al. (2003). The authors focused their study on the experience of health and illness among First Nations clients who were required to relocate from remote communities in Northern Ontario to receive kidney dialysis services at a hospital in Thunder Bay. Salvalaggio et al. (2003) noted that limited income, expensive travel costs and the extensive distances required to access health services, often led to the separation of dialysis patients from families and predictable home environments for extended periods of time. Worries about children and other family members and the home setting,

combined with the unfamiliar and unpredictable routines of the hospital setting, significantly increased clients' feelings of vulnerability and detracted from their overall ability to participate actively in their own care.

In relation to marginalization, Dodgson and Struthers (2005) stated that one way in which Indigenous clients experienced marginalization was through “forced biculturalism” defined as “the difficulties that they experienced in trying to negotiate mainstream culture, while maintaining connections with their own traditions” (p. 342), or trying to live in two worlds at the same time. All the participants in their study attributed this need to live biculturally as “a source of alienation” (p. 342). More than half of the participants felt that the disconnection from one's place of origin and its traditions that often resulted from assimilation into mainstream society was the direct cause of illness in their home communities.

Being uncomfortable in clinical situations within the mainstream health care system correlated directly with feeling like a stranger or an intruder for some clients (Browne & Fiske, 2001; Browne et al., 2000; Baker & Daigle, 2000). The female participants in the study by Browne and Fiske (2001) stated that they often felt a lack of ease when faced with mainstream social patterns of interaction. One woman in the study explained her experience in a waiting room of a mainstream clinic as the stranger or intruder as follows:

... We don't socialize together so. So it's us and them. And we feel like we're using, we're intruders on their system. A lot of times I feel that way. And

probably a lot of Native people would feel the same, I think, that we're intruding, it's their service. (p. 137)

Baker and Daigle (2000) reported that the hospital setting was often experienced by Mi'kmaq clients as a place that perpetuated feelings related to being a stranger. Clients voiced the need to withdraw into themselves which further enhanced their experience of otherness. Many reported discomfort and feelings of being alone in mainstream health care settings.

Overall, the literature stressed the importance of providing Indigenous clients with adequate content information about diagnoses and explanations of treatment plans and follow-up, in a culturally appropriate format, at the right time and in adequate depth. With respect to the use of a culturally appropriate format for health care information for American Indian family caregivers, Malach and Segel (1990) noted that:

Health care providers typically ask questions and use handouts, booklets, or in some cases dolls and pictures as communication aides. Within Indian cultures, it is inappropriate or considered taboo to look inside the body, even in pictures, or to use dolls or puppets. Health care providers need to learn from families and tribal representatives methods for communicating information without creating discomfort. (p. 227)

Based on their work with American Indian family caregivers, Garwick et al. (2002) advised health care providers to take care not to make assumptions that the health beliefs and practices of one Indigenous group will necessarily be consistent with those of

another. It makes sense that one cannot assume that two members of the same Indigenous community will value similar mainstream or traditional approaches to health and illness.

Being in control. The third overarching theme in relation to the health care encounter for Indigenous clients concerned their need to be in control of their life course in spite of health challenges. Inherent in this expressed desire to maintain a sense of control, even in the face of illness, was the need to be an active and informed participant in one's plan of care. Similar to the first two overarching themes from the literature (being respected and understood, and being comfortable), some studies did address clients' voiced positive experiences in health care interactions where their needs for self-determination in health care decision making were adequately met by the health care team. However, many studies found that clients relayed accounts where their need for adequate information to make the right health care decisions for themselves or loved ones (such as their children) was not adequately met. In the study by Salvalaggio et al. (2003), patients receiving kidney dialysis reported significant anxiety over their lack of involvement in treatment decisions concerning their care. This anxiety was further complicated by their dependence on a health care system where treatment routines were highly medicalized, confusing and did not allow for integration of traditional healers and traditional medicines. The studies by both Salvalaggio et al. and Towle et al. (2006) noted that orderly and fast-paced treatment environments within mainstream treatment environments, combined with health care workers who appeared professionally distanced and hurried, led clients to experience diminished feelings of power and control. Garwick et al. (2002) noted the frustration of clients who described the receipt of adequate medical

explanations at the time of diagnosis, but a steady decline in the provision of adequate information during the subsequent treatment and follow-up periods.

Another common frustration expressed by Indigenous clients in the literature was that care providers in the mainstream health care system lack an understanding of the importance of including of family members, tribal Elders and/or traditional healers in the health care decision making process. Dodgson and Struthers (2005) noted that it was essential for health care providers to understand the need for, and incorporate clients' preferences into the plan of care. This includes an appreciation for the fact that many Indigenous clients may take considerable time to make decisions about treatment options in that their decisions may be made through consensus with family and others outside of the health care team. Maintaining a sense of control over one's health via direct and active participation in the decision making process may be best summarized by one participant in the study by Browne and Fiske (2001) who emphasized the importance of a positive provider-client relationship that "allowed for an exchange of knowledge and contributed to personal empowerment" (p. 139).

Summary

Prior to engagement in health research with First Nations groups in Canada, it is important for one to gain an understanding of the complexity and interrelationships among the concepts of First Nations health policy and health service delivery, and the role that First Nations health research plays in informing these concepts. Perhaps more important is the need for health care providers and researchers to develop knowledge

about First Nations perceptions and experiences of health service delivery systems that have evolved from recent research and policy development initiatives.

The predominant Federal Government funding base for on-reserve First Nations health service provision varies substantially from the way in which health services are funded and delivered to non-Indigenous persons in Canada. Despite the Federal Government's legislated responsibility under the *Indian Act* (1876) for the provision of health services to on-reserve First Nations peoples, minimal efforts were invested at the national level, before the early 1990s, toward the formalization of health service delivery within First Nations communities. The growing research knowledge base concerning the disproportionately higher rate of health disparities and social inequities experienced by Aboriginal peoples as compared with non-Aboriginal peoples in Canada, led the Federal Government to enact the Indian Health Policy of 1979 and the Health Transfer Policy of 1989. Both policies were established to improve overall Indigenous health outcomes and bring about increased responsibility for, and control of health services by Indigenous communities. While the health transfer process has resulted in promoting health care leadership and greater administrative expertise among some First Nations communities, the overall health status associated within the same communities has declined. Critiques of the health transfer process have called for greater government consultation and collaboration with First Nations communities and improved financing.

A critical review of relevant research literature was conducted to assist me in developing knowledge about First Nations experiences of health services. Given that only a small amount of research has been documented specific to First Nations client

experiences in Canada, the literature search included publications (1990-2012) that addressed the expressed experiences of health services by First Nations and Métis groups in Canada, and American Indian populations within the United States. Three overarching themes from the literature describe the Indigenous client experience of health services: (a) being respected and understood; (b) being comfortable; and (c) being in control.

The first theme addressed the client experience of being respected and understood by health care providers within the larger health care system. Central to the experience of feeling respected and understood by health care workers was the client's need to be treated as a unique and worthy individual and to be listened to genuinely and attentively. This occurred primarily when clients perceived that health care providers possessed an awareness of the real life contexts within which clients experienced health and illness (such as poverty, family violence, and a lack of social supports and related resources). Experiences that made clients feel disrespected and misunderstood included interactions with health providers who appeared hurried, dismissive and did not listen attentively and with a genuine demeanor. Clients who reported not being respected and understood were more likely to remain quiet, withhold information and refrain from asking questions due to lack of trust or respect for health care providers.

The second theme addressed the client experience of being and feeling comfortable within the health care provider-client relationship and the larger environment within which health care services are received. Experiences of comfort stemmed largely from the degree to which clients felt a sense of familiarity with health care workers and the health care environment. Feeling comfortable in the receipt of health care services

was enhanced when clients felt that they knew the health care providers personally, through common community/tribal affiliation or through long-term, sustained provider-client relationships. Clients were more likely to report general discomfort and/or feelings of vulnerability if they felt like a stranger or an intruder in the health care environment, and when they had to deal with workers who were difficult to understand. Historical trauma arising from colonizing experiences such as attendance at residential schools significantly impacted clients' perceived levels of comfort within the health care system. Some clients who reported discomfort in health care encounters were likely to transform themselves by 'dressing up' or trying to appear 'more educated' or to avoid seeking health services altogether.

The third theme addressed the client experience of being in control of one's health and decisions that are made concerning the health care that one receives. It involved their experiences of perceived power differentials within the provider-client relationship and the impact of such experiences upon them. Feeling self-sufficient in relation to the management of one's health and life in general contributed to feelings of being in control. Feelings of being in control were enhanced when clients felt that they received adequate information at the right time, and in adequate depth to make informed health care decisions for themselves or loved ones. Experiences which diminished clients' perceptions of being in control included instances when health care providers did not provide adequate information to clients about their diagnoses, treatment plans and the rules of conduct expected of clients within the system. Health care providers were often noted as not acknowledging the importance of Indigenous ways of decision making (such

as by consensus) and the time that may be needed for such health care decisions to be made. Some health providers' disregarded clients' traditional beliefs and desires to include traditional healers, Elders and family members in key health care decisions. Some health care providers were perceived as disempowering and perpetrators of the client dependency.

In reflecting upon the literature review, I noted a number of overall trends and gaps in the research documentation. No study was found that focused exclusively on the client experience at a health centre within a First Nations, Métis or American Indian community. This may be in part because many Indigenous communities (especially those in rural and remote geographic areas) contain relatively small populations where the economic base may not be adequate to support the establishment and maintenance of an on-reserve health centre. Regardless, with the Federal Government's continued transfer of control over health services to First Nations communities, it has become increasingly important to know how these services are being perceived, experienced and utilized by community members.

I was unable to find any studies that specifically targeted client experiences associated with health promotion and illness/injury prevention as a priority of health service delivery. The majority of relevant studies found were focused upon the client experience of being screened, diagnosed and/or treated for an existing health problem across a broad range of service types within "mainstream" or "Western" health care settings. In an era where health promotion and illness/injury prevention services are being viewed by academics, researchers and policy makers as essential elements for the

promotion of positive population health outcomes across the lifespan, it is necessary that First Nations perceptions, experiences and preferences in relation to the utilization of such services are known and understood.

From a research design standpoint, all but three studies used a qualitative design exclusively. Among the remaining studies, one was quantitative and one employed both quantitative and qualitative methods. Three of the qualitative studies were labelled as ethnographic, four as descriptive and three as interpretive, with one other being a secondary analysis. None of the studies were labelled as “phenomenological” in design with the exception of one of the source studies used in the secondary analysis by Dodgson and Struthers (2005). Given that each First Nations community in Canada is contextually unique in terms of its geography, history, economics, linguistic heritage, and its sociocultural and political structures, I would expect that the phenomenon of the client experience of health services would vary to some extent from one First Nations community to another. A gap in the health care literature exists in terms of understanding how these and other contextual factors impact upon client’s perceptions and experiences of health services provided within their own communities.

A trend noted in the relevant literature was the underrepresentation of male client perspectives and experiences of health services within Indigenous communities. Five of the nine Canadian studies that were included in this literature review, employed samples that were exclusively female, and in the remaining four of these studies, the majority of sample participants were noted as female.

The most common data collection strategy employed across the studies was face-to-face interviews, while three studies used surveys. Focus groups were used in two of the qualitative studies and photovoice was used in one. There was significant diversity among the qualitative studies in terms of the data analysis approach used, with no two studies using the same model of analysis. Only one ethnographic study (Browne et al., 2000) mentioned the work of Max van Manen for use in data analysis. A few of the studies specifically identified the use of participatory action principles and the importance of conducting research and disseminating study findings in ways that are culturally congruent with Indigenous knowledge systems.

While I have outlined each study's strengths and limitations in Appendix C (Table Summary of the Critical Review of the Relevant Literature), a few studies by Browne (2007), Browne and Fiske (2001) and Dodgson and Struthers (2005) stand out positively in terms of the completeness of their description and appropriate application of theoretical and philosophical foundations in relation to their chosen methodologies. Given the growing emphasis in the literature on the importance of cross-cultural consultation and collaboration with researched Indigenous populations (Castellano, 2004; O'Neil, Elias, & Wastesicoot, 2005; Schnarch, 2004), I was surprised to find that only five of the fourteen studies made mention of specific efforts to include Indigenous partners in the planning, implementation, analysis and/or reporting of Indigenous research projects. Of these five studies, only two by Garwick et al. (2002), and Kurtz et al. (2008) specifically identified the use of a participatory action research approach (PAR) and wove discussion of its application throughout their accounts of the research

process. The remaining three studies by Burcharski et al. (2006), Malach and Segel (1990) and Poudrier and Thomas Mac-Lean (2009) did not mention the specific use of a participatory action research approach, but did mention the inclusion of input from Indigenous community members in the design phase of the research process.

In summary, based upon the interests and health research needs expressed to me by the First Nations community with which I was engaged, and my critical review of the relevant research, I was able to determine that the purpose of my doctoral study would be to gain an understanding of the meaning of the client experience at a health centre within a First Nations community in Southern Ontario with a primary health service mandate focusing on health promotion and illness/injury prevention. A phenomenological approach was determined as ideal because my participation both as a researcher and participant in the study would provide me with a first-hand opportunity to gain important insights on the lived client experience of health centre services within the First Nations community with which I was engaged. It would give voice to First Nations perspectives on health promotion and illness and injury prevention services on-reserve.

Chapter 3

Philosophical and Methodological Foundations

The meaning and syntax of qualitative questions inform the researcher's choices concerning appropriate theoretical and methodological foundations of a research study (Agee, 2009). Based upon my quest to gain an understanding of the client experience at a health centre within a First Nations community, I employed the interpretive phenomenological philosophy of Martin Heidegger and the hermeneutic methodology of Max van Manen. As a general term, phenomenology may be viewed as a "movement" rather than as a particular "school of thought" and its meaning varies among contemporary philosophers (Polifroni & Welch, 1999, p. 237). Phenomenology requires the researcher to identify a philosophy and methodology upon which a research study will be based, and the ultimate aim of phenomenology in nursing research is the generation of knowledge about a given phenomenon of study (Dowling, 2005; Flood, 2010).

While the writings of Heidegger (1919; 1938; 1962) and van Manen (1997a, 1997b; 2002; 2002; 2006) are representative of Western streams of thought, the cross-cultural focus of my research called for culturally-appropriate address to Indigenous methodologies as ways of generating and translating knowledge for community use. I therefore incorporated the work of Cree scholar, Professor Ermine (Ermine, 2000; Ermine et al., 2004) and writings on the use of participatory processes (Hall, 1979, 1984, 2005; Holkup & Salois, 2004; Minore, Boone, Katt, Kinch, & Birch, 2004) into the design of the current study.

In this chapter, I will first address phenomenology as a qualitative research tradition from the Western philosophical standpoints of Husserl and Heidegger and Gadamer. The concept of reflexivity will be introduced as a central posture in van Manen's methodological approach to phenomenological inquiry, in terms of its relevance to a hermeneutic methodology. In that my doctoral study took place within a collaborative partnership with a First Nations community, I will address the relevance of Indigenous philosophies and methodologies. I will justify my application of Ermine's (2004) concept of 'ethical space' and the use of participatory processes as respectful and ethical methods of conducting cross-cultural research with the First Nations community of focus.

Heideggerian Hermeneutic Phenomenology

Research methodologies represent philosophical positions on what constitutes truth and reality, and are thus often labelled as paradigms or worldviews based upon ontologies and epistemologies (Whitehead, 2004). As the researcher in this study, I had the task of ensuring that I applied my interpretation of a particular philosophical worldview of phenomenology consistently with the central research question and method that I chose. The lived experience of everyday life is the main focus of the phenomenological approach. As a methodology, phenomenology is a rigorous, systematic investigation of a topic of interest (Speziale & Carpenter, 2003). Interpretive phenomenology has gained favour as a legitimate research approach within nursing (Caelli, 2000; Mackey, 2005; Van der Zalm & Bergum, 2000). It provides a way for

nurses to study and understand the human lived experience of various phenomena associated with both nurses and clients as their recipients of their care (Flood, 2010).

The Heideggarian hermeneutic approach is based upon a form of ontological questioning . Thus, by committing to the philosophy of Heidegger, my goal was to gain an understanding of the meaning of *being* associated with the phenomenon of inquiry, rather than just to provide a description of what can be known about the phenomenon (Lavery, 2003). Heidegger viewed hermeneutics as an interpretive method which allows the researcher to move beyond a simple description of the phenomenon (Cohen & Omery, 1994). For example, while Husserl may have been interested in a description given by a client of his or her experience of a First Nations health centre, Heidegger would have searched for a deeper interpretation of words, phrases and text as a whole, to discover the collection of themes that together yield a deeper understanding of the meaning of what it means to *be* a client. In order to situate the work of Martin Heidegger (1889 – 1976) within the evolution of the phenomenological movement, it is useful to briefly address the work of Edmund Husserl (1859 – 1938) as his predecessor and professorial colleague and Hans-Georg Gadamer (1900-2002) as his student.

Edmund Husserl. Husserl may be viewed as the founder of phenomenology as a philosophy (Cohen & Omery, 1994). His work in this area grew out of his discontentment with the positivist movement within the natural sciences as a means by which to research the human experience (McConnell-Henry, Chapman, & Francis, 2009a). Husserl developed descriptive or “eidetic” phenomenology in which he was interested primarily in the epistemological “study or theory of the nature and grounds of

knowledge” (Cohen & Omery, 1994, pp. 138-139). Husserl believed that human phenomena could be described primarily through conscious awareness and experience. The philosophical foundations of Husserl’s approach were transcendental in nature in that his quest was to seek out “universal human qualities” of a particular experience (Polifroni & Welch, 1999, p. 237).

In Husserl’s descriptive phenomenology, a reductive approach is used to answer the research question and the researcher ‘brackets out’ or disconnects from any preconceived perceptions of the phenomenon of inquiry. Knowledge about a phenomenon was viewed by Husserl as derived from intentional, conscious observation of the structures or essences of the experience, without particular address to the cultural, historical or social contexts within which the phenomenon is situated and experienced (Koch, 1995; McConnell-Henry, et al., 2009a). In Husserl’s view, a reductive approach permits the researcher to critically investigate the conscious experience before one’s interpretive thoughts and precepts ultimately enter the investigative process (Cohen & Omery, 1994).

Martin Heidegger. Heidegger met Husserl through their mutual scholarly pursuits and teaching appointments at the University of Freiberg in Germany, where Heidegger first learned about descriptive, reductive phenomenology from Husserl. However, once Heidegger succeeded Husserl in a professorship, he distanced himself from Husserl and his phenomenological precepts (Cohen & Omery, 1994; Inwood, 1997; Lavery, 2003). While Husserl was concerned with the epistemological question of what one knows as a person, Heidegger’s work led him to value more the ontological

exploration of what it means *to be*, or the nature of *being*; one's existence of being in the world (Cohen & Omery, 1994). His greatest philosophical publication titled *Being in Time* (1962) stressed the importance of considering the question "What is Being?" (Inwood, 1997, p. 9) and the being of focus was the human being or 'Dasein'. Heidegger stated that "Dasein's being finds meaning in temporality. However, temporality is the condition which makes historicity possible as a temporal kind of Being which Dasein itself possesses" (1962, p. 41). Heidegger (1919) addressed the concept of culture as a "historical phenomenon" (p. 101) in that a people without a culture would be a people without a history. It is through culture that Dasein shares a common destiny with those with whom he interacts in the world through a shared history (Inwood, 1997).

Historicity provides Dasein with a context from which to understand the world (Lavery, 2003). Australian nursing scholar Tina Koch explained in the following passage how Heidegger's notions of historicity and culture mesh to provide the human being with pre-understandings about the experience of phenomena:

Human beings always come to a situation with a story or a pre-understanding and are brought into focus in order to be understood. Pre-understanding is a structure of 'being-in-the-world'. It is not something that we can eliminate, or bracket, it is already with us in the world. This is one of the most difficult notions to grasp, but unless one does, the nature of interpretation posited by Heidegger and Gadamer will not be understood. (1995, p. 831)

Based on Koch's (1995) explanation, one can conclude that both the researcher and the participants as beings-in-the-world, bring to the research process pre-conceived notions

of the phenomenon of study that are inherent in the fabric of their respective cultures and histories and that such pre-understandings cannot be set aside or separated from the data sharing and interpretive processes that follow.

Dasein as Heidegger viewed it was inseparable from the contextual experience of time, body, space and relationships with others and labelled this as being-in-the-world. Central to Heidegger's notion of being-in-the-world was the notion of Dasein's ability to be aware of, and inquire about one's own existence; to be authentically aware (Heidegger, 1962). Thus, Dasein experiences of *being there* are time and space dependent. If one alters the time and setting of an experience, then the meaning of the experience is altered as a context-specific entity (McConnell-Henry, Chapman, & Francis, 2009b).

In contrast to Husserl then, Heidegger viewed all human experiences as inseparable from time and the historical, cultural and social contexts within which they take place. Thus, in committing to a Heideggerian, interpretive approach, my focus is more ontological than epistemological, in that my focus of inquiry relates to the nature of *being a client* rather than simply describing the health care world and the First Nations client's relationship within it (Mackey, 2005).

Husserl's transcendental or universalist approach to phenomenology clashed with Heidegger's existentialist stance in that Heidegger chose to focus on what was unique about each human being (Polifroni & Welch, 1999). Some key components of Heidegger's philosophy of interpretive phenomenology are the existential elements of temporality (lived time), corporeality (lived body), spatiality (lived space), relationality

(lived other) and the hermeneutic circle (Heidegger, 1962). The four existential elements will be discussed in more depth in Chapter Six, while the hermeneutic circle as a central concept of hermeneutic theory will be discussed below. Phenomenology is referred to as ‘hermeneutic’ when an interpretive (rather than descriptive) methodological stance is taken (van Manen, 2011)

Hans-Georg Gadamer and the hermeneutic circle. Gadamer accepted Heidegger’s notion of hermeneutic phenomenology that sought to understand the deeper meanings of being in relation to a given phenomenon of study. Like Heidegger, he believed that language and understanding were integrated structural elements of being-in-the world and rejected Husserl’s position that the researcher can bracket out or set aside one’s preconceived notions about a phenomenon as a participant in the research process (Lavery, 2003). The hermeneutic circle as a central component of hermeneutic theory involves a constant movement between the parts and the whole. To understand the whole, one needs to examine its parts and to make sense of the parts, one needs to explore the whole (Smith, 2007).

Gadamer further developed Heidegger’s interpretive phenomenological philosophy with the increased emphasis on the hermeneutic circle and the importance of dialogue and the fusion of horizons. The significance of dialogue is that while the researcher and participant join in conversation within the hermeneutic circle the use of open questions and answers allows the participant to take the researcher on a narrative journey without restriction so that the voice of the client can be truly heard. Gadamer’s fusion of horizons is a metaphorical term for understanding in that the lived vantage

points of both researcher and participant fuse to form a collective understanding of the phenomenon of inquiry (Koch, 1996).

Barton (2004) further illustrated the relevance of Heidegger's hermeneutic phenomenological approach to Indigenous research pursuits by positing that the hermeneutic circle creates a space in which the researcher and participant engage in a circular process of expression, interpretation and translation complementary to the Indigenous sacred circle metaphor for developing knowledge and understanding from storytelling. The researcher and interviewee engage in a dance between the whole experience and its parts in their collective attempts to find hidden meanings in the experience. In the case of the sacred sharing circles of Indigenous peoples, the sharing of stories and traditional teachings among community members evolve in meaning over time. Both the hermeneutic circle and the sacred sharing circle are processes used for the generation of knowledge and can result in a product of new, evolved understanding for all who gather within them. Barton (2004) further asserted that hermeneutic research applications as culturally respectful of First Nations' ways of knowledge generation and translation, may foster a safe environment within which to engage participant involvement in the data collection and interpretation processes.

The hermeneutic circle is symbolically resonant with the sacredness of the circle in many Indigenous cultures around the world. An example of the sacred use of the circle in many Indigenous cultures is the *medicine wheel* (refer to Appendix A – Glossary) which is both a symbolic and concrete mechanism used for the purpose of understanding and relating phenomena.

The strength of hermeneutic methodology is in its assumption that research participants have the ability of self-knowing and thus, this research approach creates freedom and space for participants to give voice to their experiences in an informal interview format (Robertson-Malt, 1999). In hermeneutic phenomenology, there may be a number of hermeneutic circles existing simultaneously that may include circular relationships between the researcher and the data and the researcher and the participants (Smith, 2007).

I chose the Hermeneutic phenomenological approach for my research study in part because of its support in the literature with respect to the conduct of research cross-culturally and more specifically with Indigenous populations. With respect to the fittingness of hermeneutics to cross-cultural research, The Australian nursing research team of McConnell-Henry, Chapman and Francis (2009b) stated that hermeneutic phenomenology is ideally suited to nursing as a discipline because “people, their interactions and their lived experiences are the core of nursing” (para. 6).

In relation to cross-cultural research, Caelli (2000), a nursing scholar, stated that phenomenological approaches that interpret human experience as culturally constructed, rather than universally constructed, contribute to nursing knowledge development by fostering nursing’s appreciation of unique world views of lived phenomena from different cultural perspectives. Struthers and Peden-McAlpine (2005) asserted that a hermeneutic research approach is harmonious with the holistic, relational worldview of Indigenous peoples:

Phenomenological inquiry provides a vehicle to obtain implicit cultural meanings of Indigenous experiences; is a method for recording Indigenous culture, events and the essence of experiences through past, present and future time; and is a manner whereupon narratives and stories that are told can inform changes necessary for health promotion. (p. 1274)

Lavallée (2009), an Indigenous scholar in Canada, supported the use of “existential” (p. 28) or interpretive phenomenology as one method that is congruent and respectful of the protocols, beliefs and values of Indigenous peoples in Canada in that it fully engages participants in the creation of knowledge

Max van Manen’s approach to interpretive phenomenology.

Max van Manen (1997b) embraced hermeneutic phenomenology in his role as an educator and contested that central to the doing of phenomenological research is the act of writing. A clear linkage between writing and phenomenology as a form of research was captured by van Manen (1997b) when he stated that,

The aim of phenomenology is to transform lived experience into a textual expression of its essence – in such a way, that the effect of the text is at once reflective re-living and a reflective appropriation of something meaningful: a notion by which the reader is powerfully animated in his or her own lived experience. (p. 36)

Another way that van Manen (1997b) linked the action of reflexivity to hermeneutics, was to state that by reflecting upon and therefore assigning memories to a lived

experience of a phenomenon via remembering, talking, writing or similar actions, one bestows hermeneutic importance to the event.

I chose to use van Manen's (1997b) phenomenological methodology for a number of reasons. His work is informed and consistent with Heidegger's view of interpretive phenomenology. His writings clearly illustrate the role of the researcher as participant in the research process and the importance of reflexive writing which requires the researcher to document content that goes beyond what the researcher sees, and includes what the researcher feels and experiences as an active participant in the research process. van Manen's (1997b) use of the four existential elements of lived time, lived space, lived body and lived other provides the researcher with a framework for interpreting and understanding the context within which First Nations clients experience phenomena related to health, illness and service utilization. His phenomenological methodology has been well tested as a nursing research methodology (Dowling, 2005).

Indigenous Knowledge Systems and Methodologies

The Heideggerian philosophical foundation of the current study was representative of Western scientific and aesthetic notions. However as a researcher who wished to engage in a collaborative research partnership with an Indigenous community, I had an ethical obligation to select a research methodology that respected and addressed Indigenous ways of knowing, sharing and using knowledge (Castellano, 2004; Cochran et al., 2008; Kovach, 2009).

In her book *Indigenous Methodologies*, Margaret Kovach, an Indigenous scholar of Cree and Sauteaux First Nations heritage in Canada defined Indigenous

Methodologies as “the theory and method of conducting research that flows from Indigenous epistemologies” (2009, p. 20). One commonality that was noted by Smylie et al. (2003) in comparing Indigenous and Western scientific knowledge systems or ways of knowing, is that in both systems of knowledge generation, information as knowledge is the product of the synthesis of beliefs and human experience. Despite this basic similarity, Western scientific thought and Indigenous knowledge systems differ substantially. Smylie et al. (2003) described Indigenous knowledge generation as follows:

In Indigenous knowledge systems, generation of knowledge starts with “stories” as the base units of knowledge; proceeds to “knowledge,” and integration of the values and the processes described in the stories; and culminates in “wisdom,” an experiential distillation of knowledge. (p. 141)

Smylie et al. (2003) referred to Indigenous knowledge generation as circular and spiral in nature in contrast to Western knowledge creation as linear where new scientific truths replace what is viewed as outdated or no longer scientifically relevant.

In many First Nations and Métis communities, Elders and others have traditionally been keepers and guardians of many forms of Indigenous or *traditional knowledge* (refer to Appendix A – Glossary) in the form of stories and this knowledge was considered as sacred and community-owned (Castellano, 2004). Such community-owned knowledge is often referred to in the academic health care literature more formally as intellectual property (Canadian Institutes for Health Research, 2007; Schnarch, 2004). Therefore, if my research methodology was to be respectful of, and consistent with Indigenous knowledge systems and ownership, then at the very least, it required

deliberate address to Indigenous stories about their experiences as clients as a central source of research data. What is not always made clear in discussions concerning traditional knowledge and medicine is the fact that their importance extends beyond their informational value alone, in that a community's possession and use of such knowledge can serve as protective and health promoting factors in assisting Indigenous populations to cope with everyday crises (Martin-Hill, 2009). This discussion further illuminates the researcher's ethical responsibility to recognize, respect and protect the proprietary rights associated with community knowledge that may be inadvertently shared with him/her during the research process and the potential value of knowledge that is co-created by the researcher and participants as part of the phenomenological research process.

Mohawk scholar Marlene Brant Castellano described Aboriginal research as “research that touches the life and well-being of Aboriginal peoples” (2004, p. 99). Bearing this definition in mind, I had an ethical obligation to ensure all aspects of the research process, including the dissemination of the study's findings, would translate well within the Indigenous worldviews common to the First Nations community of focus; that is, that such knowledge was disseminated in ways that were respectful of Indigenous knowledge systems within this community. From the practical standpoint, such research should benefit and empower the community by yielding new knowledge that would assist its leaders, health care providers and individuals to make informed decisions and provide health services to its members that are effective and evidence-based (Schnarch, 2004).

The methods through which generated knowledge is disseminated to the researched community and to the larger First Nations collective will be a key determinant

of its academic and practical relevance and validity. Research methodologies that respect the relational nature of an Indigenous worldview are built upon the “collective value of giving back to the community”. While there are many ways in which a researcher can contribute back to the community, the most relevant methods include assuring that research addresses community’s identified needs, and that knowledge in relation to the research process and outcomes is readily accessible and useful to the community. This can only take place when a viable and trusting relationship between the researcher(s) and the researched is established from the outset and maintained throughout the research process (Kovach, 2009).

A generic definition of knowledge translation (KT) provided by the Canadian Institutes of Health Research is “the exchange, synthesis, and ethically sound application of knowledge within a complex set of interactions among researchers and users” (2006, p. 6). With respect to health research within the researched First Nations community, KT requires a focus upon the Indigenous community members as the users of such knowledge (Smylie, Kaplan-Myrth, & McShane, 2009).

Bridging Indigenous and Western Worldviews

As I became more aware of the differences between Western and Indigenous worldviews concerning health and research, I wondered how I would go about conducting a doctoral research study that respectfully, and ethically addressed these differences. The work of Cree scholar, Professor Ermine (2000), and literature sources on participatory action research methodologies provided me with possible solutions to guide me both philosophically and practically.

Ethical space and power relations. As an Indigenous scholar and researcher, Ermine (2000) noted that,

It is sometimes a gift as much as a curse to see two worldviews simultaneously, but perhaps it is necessary to have this positioning to be able to articulate an ethical research process that speaks in a language of higher possibilities than what is standard in established academic scholarship. (p. 9)

While he alluded to the ethical challenges of cross-cultural research, he voiced guarded optimism in the fact that when consciously faced with such a dichotomy in worldviews there may be opportunities for learning and growth for both cultures that might not otherwise be present when the researcher and researched group share similar forms of knowledge and cultural norms.

Ermine (2000) adapted the concept of ‘ethical space’ from the work of Roger Poole (1972). Poole stated that when two entities approach one another, each with their own intentions, an ethical space is immediately established between the two parties. In the case of Ermine’s (2000) application of Poole’s original concept, the researcher and the researched approach one another, each with their own worldviews, knowledge sets and goals for research. Ermine (2000) viewed the space of difference between both parties as a tangible chasm across which equitable negotiation and ethical protocols could be established that may be synergistic for both parties involved. What is key to the concept of an ethical space, is that when two parties meet in purposeful dialogue, it is their *differences* that create an ‘urgent necessity for a neutral zone of dialogue’ (Ermine, et al., 2004, p. 20). In my reading of Ermine et al. (2004), I interpreted the phrase

“neutral zone” as a potential space of presumptive equality of both parties. Thus, Ermine’s work provided a way of thinking or a philosophical framework within which I could participate as a non-Indigenous person in a collaborative research partnership with a First Nations community.

The researcher’s presumption of equality between the researcher and researched does not necessarily translate into a research methodology that equalizes the actual power of both parties in terms of control and decision-making within the research process (Martin-McDonald & McCarthy, 2007). Maori researcher Linda Tuhiwai Smith (1999) asserted that when researchers engage in cross-cultural research with minority populations, it is essential that they understand the inherent power differentials that exist within the researcher-research participant relationship and that the position as investigator is most often one of socially-constructed dominance. Smith (1999) further stated that it is not enough for the researcher to be well intentioned to do no harm, and to conduct a research study in ways that will directly benefit the researched group. It is important for the researcher to understand that power dynamics existing within the intimacy of a phenomenological research relationship have the potential to both to help and to harm. For example, Martin-McDonald and McCarthy (2007) noted that as White, middle-class women engaged in research with Indigenous peoples of Australia, their awareness and understanding of Indigenous health was “partial, racial and socially constructed” (2007, p. 128).

Throughout their engagement in the research process, Martin-McDonald and McCarthy (2007) became more consciously aware of their own whiteness, and perhaps

more important, realized that their social position by virtue of their race and educational status was always visible and in the minds of their participants relative to their own Indigenous experiences of colonization. Martin-McDonald and McCarthy (2007) concluded that in order to achieve culturally relevant and useful outcomes for Indigenous peoples, there is a need to pair ethically sound intentions with an ongoing critical reflection upon of one's own racial and social positioning. Without doing so, one risks upholding the very colonizing actions and outcomes that one seeks to avoid. The researcher is called upon to make concrete efforts to minimize power differentials through shared knowledge generation and joint decision making throughout the research process.

From a phenomenological standpoint, van Manen (1997b) stated that a hermeneutic methodology is essentially “a philosophy of action” (p. 154) and that an investigator who relies on a phenomenological approach, does so in a very personal way. A researcher who uses a phenomenological approach, is essentially employing a form of participatory action research that is not “external, top down” or “expert” in nature and is conducted “*by rather than for*” the researched community (van Manen, 1997b, p. 156).

Participatory action research (PAR). When research seeks objectivity to maintain separation between the investigator and the informants, there is an ethical violation of Aboriginal values of “reciprocal relationship and collective validation” (Castellano, 2004, p. 105). Research approaches and designs need to be culturally appropriate to the group of interest in order to yield valid knowledge about the specific population and to translate that knowledge into culturally suitable care. This has been the

case with many Aboriginal communities in Canada, who as a result of a multitude of negative past experiences with uninformed researchers, have developed a lack of trust and appreciation for the research process as having any positive value for their communities (Dickson & Green, 2001; Schnarch, 2004). This is particularly true in cases where they have not been invited to participate in key decisions about the subject of focus and the research methodologies used within their communities. For such populations, participatory action research (PAR), a form of qualitative research, may provide a solution in assisting them to maintain more control over the processes and outcomes of research studies that are conducted within their communities.

PAR has been used in the social sciences since the early 1970s. While this approach to research has undergone many modifications over the years, a number of basic principles have existed since its inception. Budd Hall (1979) a Canadian educator and researcher who has championed the use of PAR, stated that “the ultimate goal of research is the radical transformation of social reality and the improvement of the lives of the people involved” (p. 407). Hall contended that PAR is a suitable research approach to use with vulnerable populations and that their direct participation in all facets of the research process can promote greater community awareness of available resources, as a pathway to increased self-reliance. A PAR approach values the voice of the collective, and is therefore consistent with Aboriginal values and its use in Indigenous communities is well supported in the literature (Cochran, et al., 2008; Dickson, 2000; Holkup & Salois, 2004; Minore, et al., 2004). It is for these reasons that I chose to incorporate participatory processes in the conduct of my interpretive, phenomenological research design.

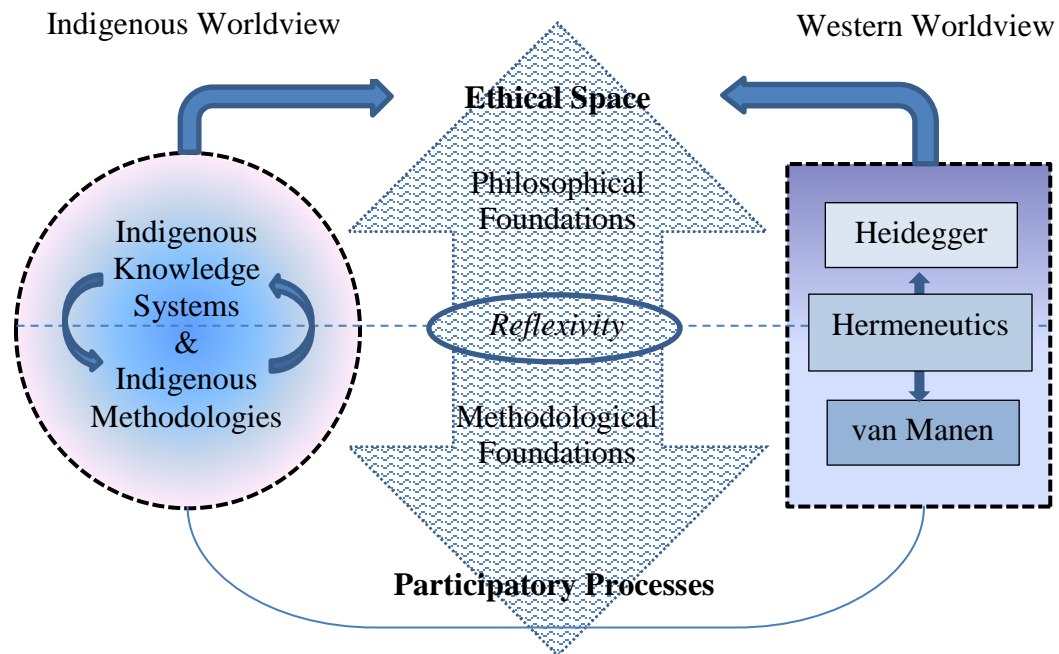
Summary

I experienced many challenges in writing this chapter in that addressing multiple philosophical and methodological concepts is not easily accomplished in a linear, paragraph-by-paragraph writing style. The philosophical and methodological foundations of a study that are situated between both Western and Indigenous worldviews must be artificially ordered so that they can be presented in some type of logical discussion sequence, when in fact, many of the concepts presented in this chapter are intertwined and inseparable from one another.

Over time, I began to see relationships between the concepts in this chapter in a diagrammatic format in my mind. I present a concept map on the following page that may best summarize how I visualized and conceptualized the interrelationships between the Western and Indigenous philosophical and methodological foundations of the current study (Refer to Diagram 1 - Concept Map of Philosophical and Methodological Foundations).

Diagram 1

Concept Map of Philosophical and Methodological Foundations



In Diagram 1, the Indigenous worldview is encased in a circle and shows the integration and spiral movement between Indigenous knowledge (in its many forms) and the application of Indigenous methodologies. The philosophical and methodological key elements of the Western worldview are housed within a square where the movement occurs within a linear and hierarchical fashion from the acknowledgment of Heidegger’s foundational philosophy to the subsequent expression of Heidegger’s ideals through the methodological application of Hermeneutics using the work of van Manen. Professor Ermine’s (2000) concept of an ethical space sits at the top of the diagram and influences the entire course of the research process. The application of participatory processes symbolically and concretely joins both the Indigenous and Western worldviews from

outset to dissemination of the study findings. Reflexivity represents the central actions of thinking and writing that take place prior to, throughout and following the researcher's actual engagement in the research process and this is shown by a large central arrow with a wavy background and dashed, open boundaries. The diagram also speaks to my understanding of my cross-cultural relationship with the research participants and the First Nations community as a whole. The next chapter further describes my stance as the Western researcher within an Indigenous research setting, based upon my extensive engagement in reflexivity.

Chapter 4

Researcher's Stance

My use of the term “researcher’s stance” as the title of this chapter is drawn from my ongoing reflexive analysis concerning my standpoint and experiences as a non-Indigenous person engaged in research processes with Indigenous peoples. As a doctoral student I have been given the time and opportunity to learn about the diverse cultures, languages, spiritual beliefs, economics, politics, histories, life ways and world views of health and healing that are associated with Indigenous peoples in Canada. In particular, I have been fortunate to work for the past six years in a research partnership with one First Nations community in Southern Ontario that chooses to open its community to graduate students.

Within this chapter, I will describe what drew me to this area of study and the path of unanticipated introspection and personal growth that has resulted. I will highlight significant strategies and unplanned experiences that helped me to build a novice-level knowledge base upon which to enter into a respectful research partnership with a First Nations community.

Michael's Story

In 1979, as a recent nursing program graduate, I took a temporary summer job as a Registered Nurse in a rural hospital in the Fraser River Valley of British Columbia to satisfy my desire for travel and adventure before subsequently settling down in more permanent nursing employment in my home province of Ontario. One warm summer night, I was finishing my 2:00 AM rounds of the patients under my care on the hospital's

medical-surgical unit. While the majority of the patients appeared to be sleeping soundly, one man in his late 40s quietly motioned me over to his bedside. From the report, I knew that he was a resident of a local First Nations community and had just been admitted to the unit with considerable pain and bleeding from an abdominal ulcer. I assumed he was in pain, but he told me, “No, I can’t sleep. Have you got a bit of time to sit down and talk with me?”

Though almost 25 years separated our ages and there existed vast differences in our cultures and life experiences, a bond of mutual trust began to build between us. During that first night, and for several nights that followed, whenever I found the time, I would steal some time away to sit with Michael. For the first time in my life, I was learning through the eyes of an Indigenous man about his life on a First Nations Reserve. Michael spoke of many things, some of which brought smiles to his weathered face, and sad stories of loss, residential school experiences, and off-reserve discrimination as an adult.

He spoke of the beauty of the land and his love for hunting, fishing and trapping; ways that were taught to him by his father and grandfather; both of whom followed a long line of tribal hereditary chiefs. He talked of bears, deer and lynx and how the land and nature were tied to every facet of his culture and spiritual beliefs. During our early conversations, I sat at times speechless, enthralled by his stories of nature and living on the land. However, as our comfort with one another increased, he began to reveal stories which made him sad and at times brought us both to tears. He grew up with several siblings, but many had since died of illness, alcoholism, gun-shot wounds and motor

vehicle accidents. His father was still living, but his mother and many of his “aunties” and grandparents had died of tuberculosis or complications due to diabetes and heart disease. Woven through many of his stories were undercurrents of poverty, poor housing and overcrowding, family violence, alcohol abuse and related addictions.

As a young and culturally naive woman who was raised in a supportive, middle-class environment, the details of Michael’s portrayal of his life on a First Nations reserve in Canada shared little context with my life. Through his stories, my eyes were opened to one First Nations people about whom I had no knowledge. The conversation that I began that evening with the son of a First Nations hereditary chief was to change my life in ways I could not have anticipated and formed the impetus for my decision 25 years later, to make Indigenous health studies the focus of my doctoral education.

Between 1979 and 2004, my nursing career included a series of consecutive employment roles in practice and education in three Ontario cities. Throughout this time, I never forgot my conversations with Michael; nor did I lose the desire to connect with and learn more about Indigenous peoples in Canada. As my career focus became more specialized in the field of community health promotion, I became particularly aware of the “relative disproportional burden of disease” faced by First Nations and Inuit populations in Canada (Adelson, 2005, p. S45). I was interested in why Canada’s Indigenous peoples bore a greater burden of health disparities as compared with other Canadians.

Beginning the Journey

By the fall of 2004, I had enrolled in a doctoral program intending to focus on First Nations Health while I simultaneously pursued sources of knowledge about First Nations populations in Canada. I made contact with a First Nations colleague at the University of Windsor where I was employed. He first directed me to government legislative documents such as the *Indian Act* (1876) and its subsequent amendments. He encouraged me to examine the documents resulting from the *Royal Commission on Aboriginal Peoples* (1991).

At the same time, I was introduced to his home First Nations community where I met the community's acting director of the community's research centre. With his permission, I was encouraged to take time to read from the wealth of historical archives at the centre. I perused many of the diaries, photographs and other historical documents held in the collection. I was introduced to personnel at the local, urban Indian Friendship Centre and with an invitation, began attending a monthly women's group. I engaged in regular dialogue with a friend and political activist of First Nations heritage from another community about the significance of history, politics, economics, geography, culture and language to First Nations communities.

As I delved more and more into the literature on the legislated colonization of Indigenous peoples in Canada, government appropriation of traditional tribal lands, and the forced attendance of Indigenous children in residential schools, my sense of guilt as a Euro-Canadian became apparent to me. My ancestral heritage that extended back to the early 1700s in North America made me feel in some way connected to the carnage,

subjugation and marginalization of Indigenous Peoples. My growing view of ancestral connectedness to those who committed atrocities under European colonization led me to a profound sense of ambivalence about my right and ability to engage in First Nations research at the doctoral level. In addition, I became aware of my overwhelming sense of “outsidedness” in relation to this First Nations community and its people. Also apparent, was my naive, but budding realization of the overt and subtle complexities and protocols inherent in First Nations patterns of social interaction. Could I really engage in respectful research with the members of an Indigenous community without causing some form of harm in the process?

As a graduate nurse, I had made a professional and personal commitment to promote health and to render no harm. A basic foundation of my nursing education was a “know thyself” credo. My nursing education had instilled in me the belief that as long as I readily and genuinely appraised and understood my personal beliefs and values, skill level, biases, and prejudices, I would be adequately equipped to provide culturally “sensitive” and respectful nursing care to those of similar or differing cultural backgrounds. Yet, the concept of self-knowing seemed superficial and inadequate. In spite of my deliberate efforts to engage in self-appraisal, and learn about my chosen populations of interest, I felt ill-equipped to take on the role of a novice cross-cultural researcher.

Observing, Writing and Learning

In 2005, I began to keep a handwritten journal of my thoughts and experiences concerning both Aboriginal research in general, and my visits to the community. My

doctoral course content had previously taught me that a research journal could serve as a record of the research process, and an audit trail, as well as an instrument in which to record and reflect upon my personal perspectives and experiences in relation to the process. At first, I found it much easier to simply record entries related to events, dates and locations of travel, the people with whom I had met and the new knowledge that I had gained. With time however, I learned the importance of writing in a two-column format. In the left-hand column I recorded events, locations, dates, and the people with whom I engaged. In the right-hand column, I learned how to record in much greater depth my underlying feelings about each event and how my beliefs, attitudes and values were modified or not modified by the experience. It was the content of the right-hand column that when examined retrospectively (and introspectively), helped me to see the immense value of making regular journal entries as a way of tracking my personal growth and making sense of my role as a novice within the context of Aboriginal research in Canada.

My Cross-Cultural Lens

One of the greatest benefits that became quickly apparent to me as a result of the writing process was that while it was important to read about First Nations history and the legacy of colonization, taking on the ownership of guilt for the atrocities committed by Europeans in North America would not result in improving my competence as a cross-cultural researcher. This realization was confirmed through discussions with individuals of First Nations heritage. One particular comment which helped me to at least place my feelings of guilt and ambivalence in a more useful perspective was expressed to me by a First Nations community Elder.

Feeling guilty for the past will not help you with your feelings of inadequacy here. Just be yourself. We do not want to be pitied. If you carry this sense of guilt, we will see it and that will not allow us to establish trust in you.

This was an important lesson that aided me in comprehending the potential negative outcomes of a cross-cultural approach based upon guilt and pity, with perhaps an underlying and unrecognized assumption of self-superiority and power.

I have learned that in preparing myself for cross-cultural First Nations research as a non-indigenous researcher, it is important to seek information that includes literature that has been authored from both Indigenous and non-Indigenous author perspectives. The learning that has taken place through direct dialogue with persons of First Nations heritage, including community leaders, scholars, Elders and community members of all ages has provided the greatest contribution to my evolving knowledge of First Nations histories and present day cultures. I recognize that in spite of what I have learned to date, the diverse cultural nature of First Nations communities supports the likelihood that I will continue to make unintended errors in relation to cross-cultural communication and protocols. The key is to indicate my willingness to learn and to accept constructive criticism with humility from those of First Nations heritage who are kind enough to offer it.

Although I was introduced to the First Nations community very early in my doctoral studies, the actual approval to conduct research in a formal partnership with the community was not received until May of 2008. The frequency of my visits to the community during the first four years, intensified as my doctoral course work came to an

end. I was invited by the acting director of the community's research centre to attend occasional meetings when researchers from other universities presented reports on their study findings related to the community. I participated in selected research centre activities and learned from other students who were engaged in graduate research there. I was referred to the First Nations health centre within the community to meet its nursing supervisor and to begin dialogue concerning a viable research question. It was during this time of community engagement that I gained valuable insight into some aspects of the history, geography, socio-economics, politics, health, culture and language. I was unaware then of just how valuable this time spent would become in contributing to both my learning about the community and perhaps more important, allowing the community to develop a level of awareness and trust in me.

I was gradually introduced to members of different organizations, community services and offices within the community, and thus became acquainted at least at an introductory level with the political and organizational structure of one First Nations community. This included a rudimentary understanding of the decision making power of the elected chief and council members and that each council member was concerned with one or more portfolios such as roads, emergency services, health and education. According to my informants, experiences with unethically intentioned researchers led the community to develop a sophisticated internal system for review of research proposals. My efforts to gain a basic understanding of some of the ways in which the community rendered decisions within its political structure, helped me to prepare for its rigorous three-tiered internal research approval process.

Unlike my observation and acquisition of knowledge concerning the unique history, geography, socioeconomics, politics and health of this particular First Nations community, my quest to understand its culture and language/communication patterns was much more challenging and experiential in nature. Scholarly books and articles provided little assistance in preparing me to be a respectful and effective communicator. Further, my observations in this area were from the perspective of a non-Indigenous woman and thus I was aware that my efforts to make sense of First Nations cultural ways and communication patterns was always sifted through my Euro-Canadian lens and compared with what I knew and understood in my own world. For example, I was invited to attend a formal monthly Research Committee meeting within the community to learn about how the committee makes decisions concerning applications for research from outside the community and the committee's involvement in treaty rights and land claims. I observed what I believed to be one of the committee members sleeping during the meeting. I could not understand how she managed to sleep while still moving her pen as if she was jotting words on her notepad. A research centre staff member later told me that it is often common for Elders to close their eyes when they are listening, so that they can focus completely on the message of the speaker. This year I had the opportunity to share with the 'sleeping' Elder my past misguided assumption of her closed-eyed behaviour during that meeting which made her laugh heartily.

Listening to the Silence

As I gained a sense of comfort and acceptance in the community, I became more comfortable engaging in dialogue with community members. In general, I made the

observation that I communicated very differently from the First Nations people that I met. I was so excited to engage in conversation that I had difficulty in slowing the cadence of my speech, and in allowing time for First Nations persons to reply before eagerly blurting out my next question or comment. One of my cultural advisors stated that this is a common problem when First Nations people attempt to communicate with non-First Nations individuals. “Non-Native people are not comfortable with silence” she said, “so if a First Nations person pauses after a sentence the non-Native person often dives in, leaving the First Nations person unable to get a word in edgewise.” It was a subtle way of teaching me to count to ten before speaking. I learned that if I just took the time to really listen to what a First Nations person was saying, more often than not, the First Nations person would start to talk again. I still struggle to maintain a respectful silence. I have learned the importance of not writing when an Elder is speaking. This is a sign of respect and I listen more attentively when I am not writing. These basic, but subtle nuances of speech and communication are only a few examples of what I observed and was able to apply to my interviewing technique in order to be more culturally respectful and attentive during the data collection process. Had I not taken the up-front time to learn what I could before engaging in this cross cultural research process, I question whether I would have ever received consideration and approval of the research study in which I subsequently engaged.

Summary

Early in my nursing career, a series of late-night conversations with a hospitalized First Nations patient under my care, opened my eyes to Indigenous peoples and cultures

about which I knew nothing. This cross-cultural experience changed my life in ways I could not have anticipated and formed the impetus for my later decision to make Indigenous health studies the focus of my doctoral education and post-doctoral program of research.

Within the first year of my doctoral studies, I was fortunate to begin the establishment of a cross-cultural relationship with a First Nations community in southern Ontario. Even during my earliest visits to the community, I quickly became aware of my overwhelming sense of “outsidedness” in relation to the community and its people. Thus began an important cross-cultural journey which required me to keep a journal for the purposes of self-reflection and self-analysis, and to record the events that contributed to my learning. I learned the importance of purposefully seeking out a variety of ways to gain knowledge concerning the life contexts of Aboriginal peoples in Canada. Examples of such activities included reading the health and Indigenous studies literature; studying relevant historical and current documents and legislation concerning Aboriginal issues; and engaging directly in social conversation and related learning activities with First Nations leaders, Elders, and other members of the community.

I have learned many lessons to date in my cross-cultural, research journey with Indigenous peoples in Canada. However three lessons in particular, stand out from the rest. The first lesson is that the process of developing nursing expertise in the area of Indigenous health and research requires a commitment to life-long learning and ongoing engagement with Indigenous peoples. Secondly, it is important for me understand that my journey within the realm of Indigenous studies will always be interpreted through my

own worldview as a non-Native, Euro-Canadian, female. Finally, learning to listen genuinely and attentively to the voice of Indigenous peoples will in the long-run, serve to be my best strategy in acquiring cross-cultural knowledge.

Chapter 5

Method

Introduction

In this chapter, I will describe how I conducted the research study guided by the philosophical foundations of Heideggarian hermeneutic phenomenology, the methodological approaches of van Manen , Ermine's (2000) notion of ethical space and basic principles of participatory action research (Hall, 1979; Holkup & Salois, 2004; Minore et al., 2004) . I will briefly discuss the evaluative framework of Lincoln and Guba (1985) that I chose to appraise the rigor of the study because of its respective relevance and practical applicability to both hermeneutic phenomenological research and cross-cultural nursing research.

Collaborative Formation of the Research Question

The use of participatory processes, necessitates the involvement of the researcher in significant up-front dialogue with community members, in order to build a preliminary picture of a research problem that is of concern to the community (Stringer & Genat, 2004). I was aware that the development of a central research question would need to be 'answerable' within the timeframe of a doctoral study, and within my means in terms of costs (e.g.: travel, transcription and related materials) and other required resources (Agee, 2009). The participatory process used in forming the research question and its sub-questions took place over a nine-month period and involved ongoing learning and discussion with staff of the health centre and research centre, cultural advisors, other program staff and community Elders.

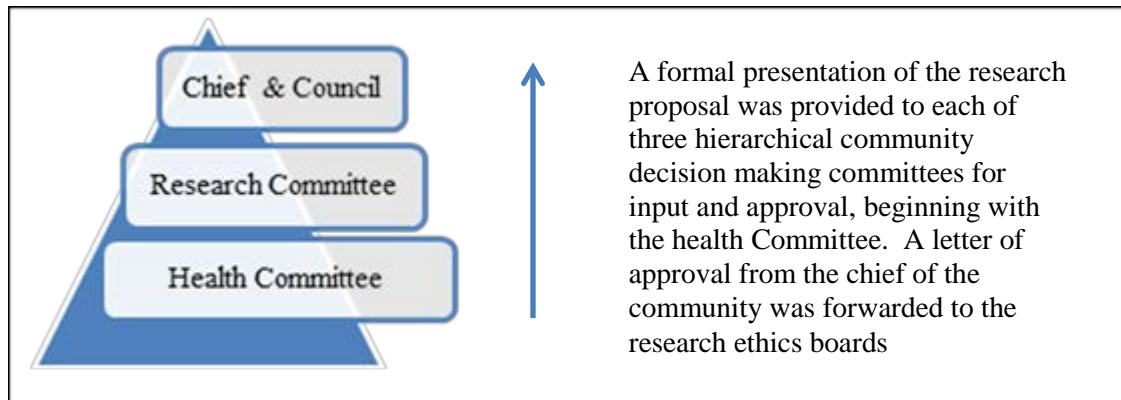
This period of learning and discussion helped me to develop a rudimentary understanding of the community's collective concerns about selected health issues and health care services access. The research question that emerged as important to the community was: What is the meaning of the client experience at a health centre within a First Nations community in southern Ontario with a primary health service mandate focusing on health promotion and illness/injury prevention?

First Nations Community Research Approval Process

I presented my research study proposal to the First Nations community in a series of three meetings as part of the process for obtaining community consent (refer to Diagram 2 - Community Research Approval Process on the following page). Each meeting lasted between one and two hours in length. Formal presentations were given sequentially to the health committee, research committee and the chief and band council. The membership composition of the health committee and research committee is drawn from registered and members. The chief and band council served as the final voice of the community in terms of granting community consent for my research project to take place within the community.

Diagram 2

Community Research Approval Process



Becoming “Open” to the Research Question

In my application of van Manen’s (1997b) method, I understood my focus of inquiry was the phenomenon of the First Nations client experience of their health centre. More specifically, I wanted answers to questions such as “Is this what it is like to be a First Nations client at the health centre?”. However, as a participant in naturalistic research with the community, my own experiences as a client of health services could in some ways possibly influence my researcher-participant role. van Manen (2011) called upon the researcher to enter into a critical self-appraisal of one’s own understanding of the phenomenon, both at the outset of a research project and to re-orient to the phenomenon throughout the process. While I am not a First Nations person and have not been a client of the First Nations health centre, I have experienced the health service client role many times within the context of my own lived experience. It was important for me to begin to orient myself to the client phenomenon by assuming that at least some

of my client experiences of health services may be similar to those of others in the client role (van Manen, 1997b).

To address this, I used my reflexive journal to write about, and reflect upon past experiences as a health services client and how such encounters may influence my beliefs about and approach to being a health care client in my present life experiences. I recognized that this form of writing helped me understand how my client experiences have affected my role as a nurse in providing care to others. My journal reflections about feeling vulnerable and physically exposed as a child in the office of my family physician and at the mercy of a strict and condescending school health nurse revealed to me the power of previous life experiences of encounters with health care providers and how such memories continue to affect my role as a health services client (and caregiver) today.

Such reflexive exercises helped me to see the true power of writing in the role of a qualitative researcher as participant. I realized that while it was important to approach the research study method with objectivity, it would be impossible to separate my preunderstandings of being a client from my role as researcher/participant. Thus the ongoing process of reflexive writing was necessary to assist me to maintain a conscious awareness of my preunderstandings of the phenomenon of inquiry and how the memories of such experiences could possibly influence the research process (van Manen, 2011). Writing about my own client experiences within the health care system helped me to further understand why my choice of a Heideggerian philosophical approach was correct, as I did not feel that I could fully ‘bracket out’ my experiences as Husserl contended as part of a descriptive phenomenological approach (McConnell-Henry, et al., 2009a).

Setting

The research project took place within a moderately-sized First Nations community of approximately 3000 band members located in Southern Ontario. Within the geographical boundaries of the community of focus, the resident composition includes band members, individuals who are eligible for band membership, as well some residents of non-First Nations heritage. The research centre staff and archival resources proved invaluable in providing me with an introduction to First Nations history, culture and about colonization and its legacy as experienced by the community as the research setting. The First Nations heritage of community members is primarily Anishinaabe. I was able to gather information about the community's primary sources of current economic sustainability such as agriculture and tourism (e.g.: hunting and guiding).

Health services in the community are offered primarily by the health centre and a separate home and community care program which delivers services largely in the home setting to the elderly and others who cope with chronic disease. The health centre's date of establishment in the early 1990s coincides with the earliest timeframe in which First Nations communities in Canada began to receive the transfer of health care funding from the Federal Government under the health transfer process as discussed in Chapter 2. Similarly, the Aboriginal Wellness and Healing Strategy was established in the Province of Ontario in 1994 to provide a foundation for health service programming within Indigenous communities (Ontario Ministry of Community and Social Services, 2008).

The health centre operates under a primary service mandate concerned with health promotion, illness/injury prevention and health screening. The services of the health

centre are provided by a multidisciplinary team of community health nurses, community health representatives and mental health and addictions workers. Other visiting health care providers offer services within the health centre's service mandates including traditional healers and contracted service providers such as dietitians, diabetes educators and foot care providers.

Beginning in 2011, a pharmacy and a small physician-staffed medical clinic were established within the community at a location separate from the health centre. Plans are currently underway to establish more community health programs in association with the health centre that will include the services of primary care nurse practitioners. (The recent addition of the medical clinic and availability of nurse practitioners were put in place after the completion of the data collection for this study.)

Residents of the community can access a variety of health services provided in urban settings within 10 or more kilometres of the First Nations community, including those that are coordinated and funded through the Local Health Integration Network (LHIN), hospitals, and health and social service professionals in private practice. All health service programming within the First Nations territory is overseen by the community's Health Committee which is made up of non-elected members of the community and an elected chairperson (council member).

Participant Recruitment

Well before the community's decision to give their approval for the conduct of the study, I was asked by a community leader as to how I would go about making the selection of interview participants as part of the data collection process. The point was

made that I was “White” and an outsider to the community. I was asked how I would go about gaining enough information about the participant volunteers to ensure that the selection of the resulting participant sample was balanced and adequately representative of community membership in terms of demographics such as educational level, socioeconomic status, experience with residential school attendance, age and other important characteristics. I was in fact grateful and relieved to hear the question because it provided me with the opportunity to ask for input from the community as to how this would best take place. Frankly, I did not know how I would be able to conduct the recruitment phase of the study as an outsider without the direct involvement of the community and I was not hesitant to admit this to the community members that were present. A number of collaborative discussions followed with community leaders and the staff of the health centre and research centre to determine the process through which the selection of participants would take place. I was later informed by the community leader that posed the original recruitment process question that my admitted realization of my lack of knowledge of community members, and my openness to ask for the advice and direct involvement of the community in the recruitment process was the key reason for her approval of the current study.

A decision was made between the community’s research committee and me that a community advisory committee would be formed from its membership for the purposes of cultural advisement and collaboration throughout the research process. One of the first roles of this committee was to provide me with guidance concerning the recruitment and selection of prospective participants from volunteers who expressed interest. The

formation and active involvement of this community advisory committee in the research study upheld the participatory process aims of this research study. Members of this committee continued to serve in both educational, advocacy and research advisory capacities throughout the research process (Strauss et al., 2001).

At the commencement of the recruitment phase of the study, I had been counselled by the study's cultural advisors regarding the importance of "getting the word out about the study" in a number of different ways (e.g.: posters, health centre newsletter, and flyers at the library) in order to make the study known to as many community members as possible. A number of volunteers conveyed their interest in the study directly to me at a community health fair and at the weekly seniors' luncheon socials. Others contacted members of the community advisory committee (CAC). My direct interface with community members provided them with access to information and answers to questions and/or concerns that they had about the study.

During the recruitment phase of the study, only basic telephone and address information was recorded concerning each research volunteer for the purposes of contact. We chose not to purposefully collect other demographic data as part of the study design. This approach was decided upon to respect the privacy of participants. However, personal demographic data that were volunteered by respondents during the interviews helped me to form an overall picture of the research sample over time and the sample's characteristics are reported in Chapter 6 – Findings.

We used purposeful criterion sampling for the selection of the study participants so that we could make use of "information-rich cases" or those from whom we would

have the opportunity to learn a great deal about the client experience (Patton, 1990, p. 169). Maximum variation sampling (Patton, 1990) was used to gain the widest possible representation of the community's band members in relation to age, gender, wellness/disease experience, spiritual traditions and lifestyle practices, and perspectives and/or experiences of health promotion and illness/injury prevention activities.

Volunteers were recruited by placing an open letter to the First Nations community in the health centre's newsletter. Copies of this letter were provided to members of the Health Committee and were posted on public notice boards in the reception area of the health centre and at the research centre. In addition, the Consent to Participate in Research / Participant Information which contained details concerning study participation was made available to those who expressed interest in participating.

My telephone number was included within the letter of information for those seeking further information about the study. All individuals who participated in the interview process were required to sign both a research consent form and an interview audiotape consent form prior to engagement in the interview process. At the request of the McMaster University Faculty of Health Sciences Research Ethics Board, I hired and trained two research assistants of First Nations heritage from the community to obtain the consents on my behalf. Two of the total number of research participants refused to be identified to the research assistants for the purpose of consent administration as they viewed their identification of intent to participate in the study to other community members as a threat to their participant anonymity. Following the advisement of my PhD

Supervisory Committee at McMaster University, I administered the consenting process for each of these participants to respectfully address their requests.

Discussions arising during the research proposal approval process within the community yielded important questions as to how the client opinions and experiences of others (beyond the sample of interviewed participants) would be heard and considered. For example, it was proposed that some community members who follow a traditional First Nation lifestyle might decline interview participation due to the use of tape recorders or due to a lack of trust of me as a non-First Nations person and as an outsider to the community. In light of this, the community wanted the research process to provide other opportunities for their stories to be included in the study if desired. I acknowledged that written communication received from First Nations community members during the research process (such as hand-written letters or electronic mail) concerning the focus of inquiry would be considered as data and that any individual who met the interview inclusion criteria, but did not participate directly in the interview process, could submit such data to me directly in writing or by other means, and they would be provided the same rights to confidentiality as that of interview participants. This information was also provided in the recruitment materials.

The inclusion criteria for sample formation were established in collaboration with the community to ensure that all participants in the sample had experienced the role of client at the Health Centre (Cresswell, 1998). The representative sample was diverse enough to provide unique stories of the client experience (Lavery, 2003). To be included in the study, participants were required to be 18 years or older and be willing to

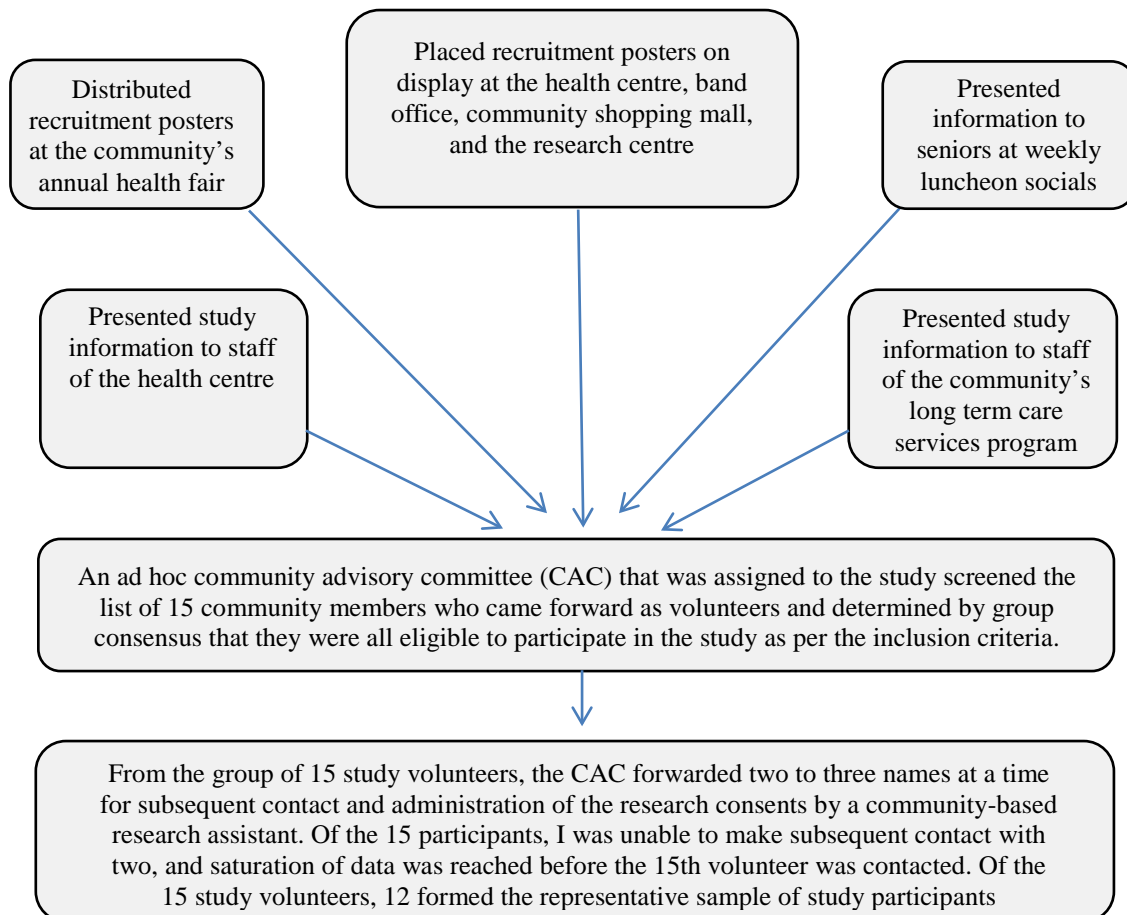
share their perspectives and/or client experiences/stories associated with the role of client as recipient of health promotion and illness/injury prevention services of the Health Centre. Participants were required to be registered band members or to be eligible for band registration. Individuals were required to be fluent in English. Although an interpreter who was fluent in the Ojibwe language and English was made available during the interview process if requested, no participant asked for one to be present.

In order to form a participant sample that was as diverse as possible in gender, age, marital status, disease experience, socio-economic background, education, lifestyle and value systems (e.g., tradition versus contemporary western views) among eligible community members, the community asked that I make multiple efforts to be ‘more visible’ and accessible to community members during the early phase of the recruitment process and to engage in dialogue with various sub-groups of the population.

To address this request, I attended a number of social events chosen by the community to conduct brief, user-friendly, and culturally appropriate presentations about the research project. This included my attendance at a number of social events including the weekly luncheon socials with the community’s senior population, a family health fair at the community area and presentations at selected formal service organizations within the community. Please refer to Diagram 3 on the following page for an illustration of the Recruitment and Sample Formation Processes.

Diagram 3

Recruitment and Sample Formation Processes



As an outcome of these events, a number of community members came forward to me and indicated their interest in participating in the study interviews. The only information asked of them at this time was their name and a method of contact (telephone number or address with which I could make subsequent contact). Through word-of-mouth, others contacted members of the advisory committee to indicate their interest in participation. At this point, one member of the community advisory committee became my primary contact and collaboration with other members of this committee took place

as necessary to reach consensus regarding individuals who I could then contact for the purposes of consent.

Demographic characteristics of many of the participant volunteers were often known by the members of the community advisory committee such as approximate gender, age, marital status, religious affiliation, kinship ties, education, socio-economic, and general disease experience, and this knowledge assisted them in selecting participants of diverse backgrounds for the sample. As a number of diverse participant characteristics were revealed voluntarily to me through participants' sharing of their stories and perspectives, I came to understand the inherent necessity of the involvement of a cultural advisor from inside the research community to guide me as the outside researcher in the formation of a balanced and diverse purposeful criterion sample. (The characteristics of the participant sample are discussed in Chapter 6 – Findings.)

Sample

Within this qualitative research project, the goal in the sampling strategy was to employ a sample that is small enough to allow me to complete a deep analysis of the focus of study, yet large enough in size to ensure a new and rich understanding of the experience (Sandelowski, 1995). The actual sample size was dependent upon the number of interviews that were required to allow me to arrive at a point when no new information came forth in the data collection process (Lincoln & Guba, 1985) . A range of eight to twelve adults from First Nations community were sought for two interviews each, approximately four to six weeks apart. The sample included 12 participants at the point of theme saturation; seven females and five males.

Data Collection

In this study the methods of data collection included in-depth interviews, reflexive journaling and all written correspondence received by me from members of the community concerning the focus of inquiry. I collected data over a six-month period from May to November 2009.

Interviews. As an outsider to the community who had not personally experienced the phenomenon being investigated, in-depth interviews were chosen as the primary data collection method so that I could learn the meaning of the experience from the perspective of multiple participants (Johnson, 2001). Using interviews as the primary method of data collection was congruent with a hermeneutic design in that it allows for “collaborative quality of conversation lends itself especially well to the task of reflecting upon the themes of the notion of a phenomenon under study” (van Manen, 1997b, p. 98). In preparing for the interview process, I familiarized myself with the literature on the research interview as a data collection strategy. The term ‘interview’ has its linguistic roots in the old French language and would have roughly translated into English as “to *see* one another” (Narayan & George, 2001, p. 820). This ‘view’ of the term ‘interview’ helped me to visualize the interview as more than just an exchange of words between two people. If I was truly able to “see” the other (interviewee), then the use of participant observation of non-verbal behaviours held equal importance to the spoken word. Prior to the first interview, I developed a brief guideline for the transcriptionist to use to signify pauses, sighs, laughter, and related non-verbal behaviours within the transcript. After each interview, I made note of particular points in the interview where I had observed a

participant's expression of strong emotions or exhibited behaviours that may not have been easy to detect on the audiotape. I was later able to match my notes with the typed transcript text.

Employment status was a significant demographic in terms of its effect on each participant's interview availability. Some of the employed participants worked outside of the community or worked in seasonal farming employment within the community, which made the scheduling of interview appointments challenging. A high rate of unemployment in the community created transportation challenges for many of the participants. This required me to be very flexible and accommodating in terms of my availability for day, night and weekend interviews, and to be willing to travel to each participant's interview location of choice.

All interviews were audio-recorded. Participants were required to sign a consent to allow for the tape-recording of the interviews. This consent form clearly outlined the participant's right to withdraw from an interview by requesting that the tape recorder be stopped at any time during the interview. I was the sole interviewer for all of the interviews to promote consistency within the data collection. Field notes were recorded in my reflexive journal as soon as possible after each interview to summarize observations, and reflections of the interview process and content. I resisted whenever possible from writing any notations down during the interview so that I could be fully attentive to the speaker and honour First Nations ways of respectful communication.

I began each interview conversation slowly by explaining the purpose of the study and allowed time for the participant to feel comfortable with self-disclosure before

moving to the key interview questions (Johnson, 2001). I ordered the list of semi-structured questions and their corresponding prompts in the Interview Protocol (Appendix D) in such a way as to pose least intrusive questions first, followed by more intrusive questions. Questions concerning events associated with the client experience were asked first. Questions concerning the participant's knowledge and the meanings he/she assigned to these events were asked second. Finally, I reserved more intrusive questions that pertained to the feelings, beliefs and attitudes participants ascribed to their client experiences to the latter part of the interview (Price, 2002, 2004). Refer to Appendix D for a copy of the Interview Protocol that includes the five open-ended sub-questions that provided some structure to the interview process, as well as possible prompting phrases associated with each of the five questions.

Aside from addressing the importance of remaining consistent in my use of the interview protocol questions within each of the initial 12 participant interviews, I needed to pay close attention to my verbal and non-verbal behaviours during the interviews and to respect local First Nations ways of communicating based upon what I had learned from the scholarly literature, First Nations community leaders, Elders and my cultural advisors. The literature taught me that Aboriginal peoples in Canada are more likely to communicate in a highly contextual manner, while most North American-born individuals tend to be low-context communicators (Srivastava, 2007). One who communicates using high context communication methods tends to convey a message less explicitly, placing more emphasis on non-verbal expression. It is important for the speaker to allow more time in the interaction for the high context communicator to hear

and process the information received. North Americans as low-context communicators, tend to make their message more explicit in the spoken word, often repeating the verbal message to ensure that it is understood, and may frequently misinterpret the low context communicator's natural verbal silence as agreement or lack of interest (Srivastava, 2007).

In reflecting upon this information and my post-interview journal entries in the early interview process, I noted that I had a habit of showing the participant often that I heard what they said by frequently saying “uh-huhn” and “yup” and this was readily apparent in the transcripts. An Elder from the community once told me that older First Nations peoples and those who live more traditionally may interpret frequent affirming sounds from the listener as “hurry up” instead of “yes, I hear/understand you”, thus leading First Nations individuals in some instances to stop talking altogether.

When I tried to deliberately suppress my excitement in being part of the long-awaited interview process with First Nations participants by trying to stay silent, my high level of energy often dissipated through other distracting behaviours such as fidgeting with changes in position of my hands and frequently changing my seated position. My efforts to maintain silence and concentrate on the spoken word of the participant manifested (at first) through unknowingly staring with unrelenting direct eye contact at the participant. Srivastava (2007) noted that low-context communicators are often uncomfortable with direct eye contact and a community Elder confirmed this by telling me that traditional Elders customarily avoid direct eye contact.

Early in the research process, my long-held scholarly interest in the study of how human archetypes manifest in one's covert and overt behaviours led me to write the

following journal entry after my initial interview with a participant, whose self-assigned code name was “Venom”:

Listening to the first eight minutes of the interview went fairly well, although I talked too much. I am not sure what happened at the eighth minute mark though because I totally took over the conversation and volunteered comments not asked for. Venom could only insert a short ‘yup’ or ‘yeah’ into the conversation before I went on. I was obviously unaware of how I was leading, actually monopolizing the conversation. Is that what I do all of the time? I saw a side of myself that I did not like – the prophet, the knower. I seemed to enter the interview as the seeker, but the knower took over. Intrinsicly, I have always valued the role of seeker more than that of the knower. But doesn’t being a scholar require me to be both? Perhaps these two archetypes are two sides of the same coin? Obviously I need to work at becoming more balanced between the knower and the seeker. I have learned here that in my striving to become more genuine as a listener and a seeker of knowledge, I need to find more ways to be quiet and listen (not just to quiet myself to be quiet).

This interview experience and journal entry brought about one of many turning points in my understanding of my role as both researcher and participant within the interview process and helped me to determine some of my primary interview skill development needs. The experience helped me to understand why writing and reflection are so central to van Manen’s (1997b; 2002) method of data analysis. It is essential for the researcher to recognize the importance of ongoing self-reflection and self-

understanding, and to be aware of one's potential to impact the data in the co-creation of knowledge with participants.

In spite of this new understanding, I went through the initial interviews with about eight participants before my overall comfort with the interview process resulted in a more relaxed posture and greater ease with periods of silence. Even then, participant stories could easily arouse my excitement and enthusiasm, thus requiring my conscious efforts to remain calm and to listen attentively. Perhaps, the most important thing that I learned was that my deliberate efforts to stay quiet and calm during participants' verbal sharing of stories actually detracted me from really *seeing*, *hearing* and *understanding* their spoken and non-verbal communication and their intended meanings. It was a liberating experience when I finally began to acquire some basic skills in listening attentively and quietly without extensive conscious effort. It was only then that I began to truly honour, respect and value the shared knowledge and stories of each participant. Perhaps this is best stated by Motari (2008) who said "When the phenomenologist gives open and full attention to the other, then he/she activates a receptive disposition, that is, the readiness to welcome the reality of the other faithfully" (p. 15).

van Manen (1997b) identified three types of silence which he referred to as literal, epistemological and ontological silences. He referred to the concept of literal silence simply as the "absence of speaking" (p. 112). Epistemological silence is the momentary silence that takes place when one is rendered speechless by an event but there exists a deeper knowing that cannot be readily stated. Ontological silence was referred to by van Manen as somewhat of a pleasing silence; a moment in which one can appreciate the

wonder of something known. From my interpretation of these terms, my greatest challenges occurred in maintaining literal and ontological silence in interview conversations. The seeker in me stayed only briefly in the moment of appreciation of new knowledge discovered and then I routinely dove into conversation in the attempt to find out more. It is the epistemological silence that I may have had the greatest skill at maintaining. This may be in part because of the high emotion that touches me at such moments and renders me both intellectually and *physiologically* speechless; that is, there is no voice with which to speak.

My understanding of the hermeneutic approach assisted me in gaining a deeper understanding of human experience by paying particular attention to the nature and meaning of the spoken language of the participant (Robertson-Malt, 1999). I needed to take a critical approach to the selection of the vocabulary that I used when interviewing a participant so that I minimized the influence of my cultural values and assumptions (Christopher, McCormick, Smith, & Christopher, 2005). All of the interview questions and the interview protocol were initially developed in consultation with the health centre's First Nation nurse manager to ensure the use of culturally-appropriate words and phrases. To further validate the appropriateness of the interview question wording, all questions were pre-tested with members of the appointed community advisory committee and a pilot interview was conducted with a staff member from the research centre prior its inclusion in my formal research proposal. The pilot interview participant was appropriately consented and was informed that her responses would not be included as part of the actual study data collection. Having piloted the interview questions prior to

their use for the first interview, I felt a degree of safety when using the questions verbatim within the interview process. However, it was in general dialogue that my vocabulary gave away my cultural biases as situated within a dominant culture. On one occasion during an interview, I asked a participant if he preferred to visit a traditional healer or a ‘normal’ health care provider when he was in need of health care information. Immediately I recognized that using the term ‘normal’ was culturally disrespectful and revealing of my Western health care biases by implying Western health care providers were the preferred and expected norm and that concepts are measured against a Western norm.

I expected that my research questions would change during the data collection process in the follow-up interviews as accounts of events, their expressed meanings, and associated beliefs and values were elicited from the varied perspectives of participants that helped me to understand the phenomenon more fully (Patton, 2002). New research questions were used for the second interview to more fully explore each participant’s expressed perceptions and experiences identified during the first interview. To minimize the possibility of my misinterpretation of participants’ verbal and non-verbal communication, the second interview was conducted to provide direct and collaborative communication with the participants concerning the accuracy of my interpretation of the data. Paths of inquiry that resulted from initial data interpretation guided the wording of questions in subsequent interviews to provide a richer, deeper understanding of the phenomenon (Crist & Tanner, 2003).

Within the First Nation community of focus, I learned that the traditional cultural practices of some community members include the offering of a gift as a respectful sign of appreciation when knowledge is shared by one First Nations person to another. Among Ojibwe (*Anishinaabe*) peoples, one might give a gift of sacred tobacco which has long symbolized peace and healing (Struthers & Hodge, 2004). However, one cannot assume that tobacco conveys the same symbolic meaning for all First Nations (Daley et al., 2006); nor can one assume that all First Nations individuals live in traditional ways. This is one of many instances throughout the research process where my understanding of Ermine's (2000) concept of ethical space and basic principles of participatory action research influenced my thinking and actions. I made the assumption that I did not have adequate knowledge of the community's cultural practices associated with gifting for knowledge given, and that I needed to engage in dialogue and decision making with the community in order for the most culturally appropriate research participant incentive to be determined.

It was important that the chosen incentive was relevant to the needs and cultural practices of a broad range of participants, and that its acquisition was within the financial means of my research budget. A collaborative decision was made to offer each participant one *No Frills*TM grocery store voucher in the amount of \$25.00 at the conclusion of each interview in which he/she participated up to a maximum total of two vouchers if both a first and second interview were completed. The monetary value of the incentive was consistent with incentives offered within other research studies that had recently taken place in the community. This resulting incentive option was discussed

with a research ethics officer at the research ethics board office of McMaster University. All twelve participants were offered and accepted a total of two \$25.00 gift certificates each in exchange for their involvement in the study.

Opportunities for non-participant input. Multiple opportunities were provided during the research process for participants who were not selected to participate in the interview process to communicate to me via telephone, letter or electronic mail. I did receive one letter by electronic mail in 2008 prior to the beginning of the recruitment phase from a community member who voiced concern regarding my presence in the community as a non-First Nation person about to conduct research related to the Health Centre. However, no other forms of written or verbal communication were received from community members during the period of data collection other than from those who chose to make direct contact with me for the purposes of indicating their interest in being interview participants.

Reflexivity. In hermeneutic phenomenology, the researcher commonly keeps a detailed reflexive journal which serves both as a form of data and as a valuable tool for data interpretation and researcher self-reflection on his/her own perceptions and experiences of the phenomenon (van Manen, 1997b). Davies and Dodd (2002) stated that the process of reflexive journaling and analysis provides the researcher with the capacity to reflect especially on the “unexpected or contradictory” research findings as valuable sources of new knowledge.

With respect to the practice of hermeneutic phenomenology, reflexivity can be defined in a number of ways. Finlay stated that reflexivity is a “thoughtful, conscious

self-awareness” (2002, p.532). She further noted that reflexivity can often be confused with the act of reflection. Finlay differentiated these terms by using the notion of a continuum where reflection at one end refers to one’s thinking about something at some distance, whereas, reflexivity at the other end of the scale connotes a much more “immediate, continuing, dynamic and subjective self-awareness” (p. 533).

Davies and Dodd (2002) extended the definition of reflexivity by stating that it requires one to engage in a constant accounting of one’s decisions during the research process that includes a critical self-assessment of one’s ideas, and open discussion of one’s research experience. In essence, through constant writing in my reflexive journal, I recorded my lived experience as a researcher and research participant while moving simultaneously between awareness and experience (Finlay, 2002).

A clear linkage between writing and phenomenology as a form of research was captured by van Manen (1997b) when he stated that

The aim of phenomenology is to transform lived experience into a textual expression of its essence – in such a way, that the effect of the text is at once reflective re-living and a reflective appropriation of something meaningful: a notion by which the reader is powerfully animated in his or her own lived experience. (p. 36)

I understood that my participation in the action of reflexivity through remembering, talking, reflexive writing and the assignment of memories to the client experience of the health centre would bring hermeneutic importance to the event (van Manen).

The reflexive journal for this study was initiated in 2004 at the time in which I was first introduced to the researched community and it continued to serve as a medium through which to record, reflect upon and evaluate my experiences as a research participant in terms of my own beliefs, values, experiences and biases. The journal served as an audit trail of research events from my perspective as a researcher including dates and decisions made at specific points within the process.

Data Analysis Approach

In this hermeneutic phenomenological study, my interpretive goal as the researcher was to find the meanings that were embedded in the words and phrases expressed by interviewed participants. In addition, I used my reflexive journal to record my own meanings of the health centre client experience and incorporated these personal understandings into the overall data interpretation process (Koch, 1999).

Max van Manen recommended three approaches for “uncovering and isolating themes” within a given text (1997b, p. 97). This meant that in staying true to van Manen’s method, I would approach each interview transcript in three different ways: through the use of repeated wholistic readings, selected readings of content and a detailed line-by-line analysis. Refer to Table 1 - van Manen’s Three Approaches for Isolating Thematic Statements for a brief summary of these approaches that can be found on the following page.

Table 1

van Manen’s Three Approaches for Isolating Thematic Statements

| van Manen’s Three Approaches for Isolating Thematic Statements | | |
|--|---|--|
| Approach | Question To Consider | Action |
| 1. Wholistic reading | “What phrase may capture the fundamental meaning or main significance of the text as a whole?” | One then tries to express that meaning using a phrase |
| 2. Selective or highlighting | After reading the text several times one considers the following question: “What statements(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described” | The statements once identified are highlighted or underlined |
| 3. Detailed or line-by-line analysis | “What does this sentence or sentence cluster reveal about the phenomenon or experience being described?” | One then documents what is revealed |

(van Manen, 1997b, pp. 92-93)

Whenever possible, I listened for the first time to the entire audio recording on the same day as the interview took place and made notes of my observations about the interview in my reflexive journal. A transcript of the interview was completed by the transcriptionist as soon as possible after the interview took place to minimize the length of time between the interview and the interpretation of its content. I created a written guide for the use of selected symbols in the transmission format (e.g. for indicating pauses in conversation) to promote consistency in transcription of the data. I asked the transcriptionist to mark all content that was difficult to discern with yellow highlighted

text so that I could review each of her transcripts for clarification and correction if needed.

Upon receipt of each typed transcript, I began by reading it in its entirety several times. Knowing myself as a ‘person of detail’, I found it difficult at first to find a phrase that captured each participant’s meaning of the client experience in my wholistic readings of each transcript. The greater the size of the interview content, the more difficult was my task to find an overriding meaning. This was particularly difficult in regard to my interviews with Colt and Hucks in that each of these initial interviews lasted well over two hours in length. At first, everything the participants said seemed important to address. I easily became overwhelmed by the extensive amount of data that resulted from the completion of each transcript.

Early in the research process, I adopted the use of the QSR International’s NVivo 8[®] data coding software as my primary resource for data coding. While the NVivo 8[®] version of the software included sophisticated capabilities that would allow me to run queries on the data and even develop graphic models of themes, my use of the software was confined mostly to van Manen’s second and third activities mentioned in Table 1, related to selected reading of transcript sections and line-by-line analysis text. The greatest advantage that I noted in using the software was its ability to allow me to scroll through the interview texts and to code data to themes and subthemes with relative ease. The fact that the theme tree could be modified as more transcript data was added, was another positive aspect of the software. However, I felt the need to read each transcript in hardcopy and to hand code the data at times. I expect that my overall comfort in the use

of the NVivo 8[®] software resulted primarily because I *began* the coding process and the establishment of my initial, rudimentary theme tree within the software view. In essence, it was the predominant method of coding within which I engaged. Therefore, my use of hardcopy transcripts provided a secondary method of hand coding as an alternate view of the data.

According to van Manen (1990), a theme is something that appears often in text. “Phenomenological themes may be understood as *structures of experience*” (van Manen, p. 79). Therefore, the themes that were derived represented an element of the lived experience of the phenomenon. Thematic analysis evolves through an examination of the transcripts in whole and in their parts. That is, the researcher begins by reading each transcript a number of times as a single whole unit. Additionally, line-by-line analysis of the spoken words, phrases and sentences of the participant are examined to look for recurrent themes. Benner described this movement between the examination of the whole transcript and its parts as forcing the interpreter to “shift from understanding and imagining dwelling in the world of the participant to distancing and questions the participant’s world as other” (1994, p. 116). Through a process of interpreting the emerging themes, I attempted to define the *essence* or a more enlightened, deeper understanding of the lived experience of the phenomenon as the research outcome. Thus, I anticipated that a new, deeper, understanding of the health centre client experience would come about.

My decision to use van Manen’s methodological approach to data analysis was largely based upon van Manen’s writing style and explicit love of writing. That is, my

reading of van Manen's (2002) introductory chapter in his edited text titled *Writing in the Dark* inspired me to regard my reflexive research journal as something more than a record of events and as a treasury of personal thoughts, and perspectives about the research process in which I was engaged. The following passage in particular led me to understand even at a novice level, the power of good phenomenological research as a rich vehicle for creating new knowledge about the lived experience of a phenomenon:

A particular thing sometimes happens when a phenomenological text is read aloud. The audience responds with silence. It is as if nobody has anything to say. There is nothing to say. But this sudden silence is not so strange if one reflects on what is actually happening: the listeners have been drawn into the textual meaning and they are struck with perplexity, the silence of wonder. (p.4)

Max van Manen defined phenomenology as “a systematic attempt to uncover and describe the structures, the internal meaning structures, of lived experience” (1997b, p. 10). Thus, in van Manen's approach to thematic analysis, the researcher is concerned with discovering the phenomenological themes that make up the experiential structure of a lived phenomenon. Metaphorically, van Manen compared phenomenological themes to “... knots in the web of our experiences, around which certain lived experiences are spun and thus lived as meaningful wholes” (1997b, p. 90). The collection of themes leads to a rich description of the phenomenon. Therefore, the interview transcripts of participants that contained their descriptions of their lived client experience of the health centre provided a textual canvass from which I could discover the underlying themes that define

the experience as a whole. To increase the credibility of the findings of the study, I involved members of my PhD Supervisory Committee in the interpretation of the data (Lincoln & Guba, 1985)

Rigor

In this study, I applied an integration of both Indigenous and Western philosophies and methodologies. Therefore, the judgement of the study's rigor requires me to address both the Western academic and Indigenous worldviews of trustworthiness. From a Western academic standpoint, rigor may be viewed as “the authoritative evaluation of good research and the unspoken standard by which all research is measured” (Davies & Dodd, 2002, p. p. 688). Within the last two decades, the nursing literature has provided researchers with a variety of criteria for evaluating the rigor of qualitative research. In light of the complexity of hermeneutics, the researcher's selection of evaluative criteria for trustworthiness or rigor needs to be congruent with the identified area of inquiry (Davies & Dodd, 2002; Koch, 1996).

My research study used an interpretive phenomenological design to gain an understanding of the client experience associated with a health promotion and illness/injury prevention health centre within a First Nation Community. Lincoln and Guba (1985) offered four criteria that the qualitative researcher can use to evaluate the overall trustworthiness of a research study. They referred to the four criteria as “credibility, transferability, dependability and confirmability” (p. 300). Lincoln and Guba (1985) stated the act of evaluating the trustworthiness of a qualitative research study requires the researcher to address the following overriding question: How can I convince

myself and others that the findings of the current study are important and worthy of consideration? I offer below my discussion of each of the four evaluative criteria and how they were addressed in the conduct of my doctoral study.

Credibility. Lincoln and Guba's (1985) description of credibility is strongly aligned with the concept of "truth value" (p. 294). In order to address the criterion of credibility, I need to ask myself how I can demonstrate that the findings of the current study illustrate a true and accurate account of the client experience of the health centre. I need to be able to demonstrate that the study's findings are judged as credible from the point of view of the participants and the broader First Nations community within which the study took place. Among the actions that Lincoln and Guba (1985) noted as central to the establishment of credibility in qualitative research are "prolonged engagement", "persistent observation", "triangulation" (p. 300), "member checking" (p. 314) as a distinct form of triangulation and "peer debriefing" (p. 308).

One of the reasons that I chose Lincoln and Guba (1985) over other sets of qualitative criteria was because of the way that Lincoln and Guba (1985) addressed the truth value of both the data and the resulting findings of data analysis. My use of the actions of prolonged engagement, persistent observation, data triangulation, member checking and peer debriefing under Lincoln and Guba's (1985) credibility criterion all resonated well with my cross-cultural stance as the researcher, participant and outsider to the community.

Prolonged engagement and persistent observation. I began use of the techniques of prolonged engagement and persistent observation when I first connected with the

community through personal invitation in the fall of 2003 and it was not until May of 2009 that I actually began the process of data collection. The period of time spent with the community of focus should be frequent and long enough to allow the researcher to detect what Lincoln and Guba (1985) referred to as “distortions” (p. 302) or anomalies that might seep into the data. Lincoln and Guba (1985) stated that prolonged engagement facilitates the investigator’s breadth of knowledge *breadth* about the researched population and setting, while the action of persistent observation contributes more to one’s *depth* of knowledge in specific subject areas.

That period of prolonged engagement served several purposes. It provided the community with time to get to know me as a person and to build trust in my intentions. It provided me with essential time and opportunities to learn about the people and their community and to develop a level of self-understanding as an outsider to the community. My reflexive journal was the location in which I recorded my observations and often recorded my feelings and experiences associated with those observations.

The most significant, positive outcome of my prolonged engagement with the community was the co-development of the research question in order to address the health research needs and preferences of the community. In partnership with the ad hoc community advisory committee, I made every possible effort to promote awareness of the study through the use of a clearly-stated and detailed letter of information and informed consent process. I collaborated throughout the research process, on a frequent basis with the director of the research centre and staff, representatives of the ad hoc community advisory committee and met regularly with my linguistic advisors. This was done in

order to establish and maintain a culturally and linguistically relevant research process and to ensure that the method and content of dissemination materials were conducted in a manner that was useful to the researched community.

All participants received the same detailed written information about the study and were asked to sign both general research consent and audio consent forms. It is interesting to note Maori scholar Linda Tuhiwai Smith's (1999) statement that in many Indigenous cultures, the act of seeking a community's or individual's consent is not so much aimed at getting their permission to ask them research questions, as it is to ask for their trust and belief in the credibility of the researcher. To maintain consistency in the data collection process, I conducted all of the participant interviews myself. The interview protocol was used to guide all initial interviews with participants and I attempted to complete all follow-up interviews within four to six weeks of the initial interview. However, necessitated participant travel to visit relatives in other communities and the acquisition of short term employment opportunities off and on-reserve (such as seasonal harvesting activities) were two of the variables that made a six-week maximum window of time between the first and follow-up interviews difficult to maintain in a few instances.

Triangulation and member checking. Two methods that I used to foster the credibility of the current study were triangulation and member checking (Lincoln & Guba, 1985). While the authors listed member checking as a type of triangulation, they made a significant distinction between the two terms:

Triangulation is a process carried out with respect to *data* – a datum or item of information derived from one source (or by one method or by one investigator).

Member checking is a process carried out with respect to constructions ...

Member checking is directed at a judgement of the overall credibility, while triangulation is directed at a judgement of the accuracy of specific data items. (pp. 315-316)

To judge the accuracy of the captured data, triangulation was carried out through my multiple readings of the typed transcripts against the actual audiotaped recordings. A participant's entire transcript was shared with the participant at the follow-up visit which served well to allow participants to review what they had stated (especially where a period of four to six weeks between the first and follow-up interviews was exceeded) and to correct any words or phrases that were misunderstood by the transcriptionist. In a few instances, participants used terms or phrases from the Ojibwe (*Anishinaabe*) language and the sharing of the entire transcripts allowed me to verify that what the transcriptionist and I had heard and our English translation of it was correct. For example, the term "samma" was mentioned in a few interviews during discussions about traditional and sacred medicines. It was not until I heard the audiotape recordings and spoke with participants who used the term, to verify that the Ojibwe meaning of the term was used to infer sacred tobacco. Many participants stated that the opportunity to read the entire transcript rather than just my summary of it was their preference and this action brought about greater transparency in our researcher-participant relationships.

Member checking was carried out through the use of the follow-up interview. Participants were able to evaluate the degree to which my interpretation of the data matched the intended meanings of their shared stories and experiences. This was accomplished through mutual dialogue about the transcript and their comments concerning my written interpretive summaries. I received validation of the accuracy and “truth value” of my interpretation when participants provided their evaluative feedback. For example, one participant stated, “*Yes, I read though it ... Looking though the summary ... you pulled out the main points and there are a few things that I can build on*”. Another participant demonstrated the strong degree of importance she attached to her role as a research participant and her role in reviewing her transcript and my interpretive summary of her transcript when she made the following statements during her second interview:

I find it quite well done ... I don't ... there isn't anything that I'd like to change ... but adding on ... If I want to add on, I would probably have to read it over about ten times and I want to read the interview again [after the follow-up interview is over] before I decide if I want to add any more. I can call you if think of anything.

The community requested another form of member checking that will take place after the defence of my dissertation, as part of the knowledge dissemination process. The director of the research centre stated that I will be asked to present a summary of the study process and its findings to a number of small groups within the community, on different occasions, including to the health and research committees, the health centre and research centre staff, the chief and council and other groups such as the residents of the

seniors' centre within the community. He indicated that this is an important way to provide community members with differing opportunities for the sharing of knowledge about the study's process and outcomes and to engage in dialogue about the relevance of the findings to their collective client experience of the health centre. He indicated that such knowledge sharing meetings are often held to celebrate the completion of the study and such events are sometimes paired with a celebratory feast. Smith (1999) echoed this Indigenous practice of celebrating the completion of a community's involvement in research and its outcomes with social gathering and the sharing of food in her book *Decolonizing Methodologies: Research and Indigenous Peoples*: "The family [as participants in a student's research project] were waiting for her; they cooked food and made us welcome" (p. 15).

Peer Debriefing. Among its stated purposes, Lincoln and Guba (1985) stated that the process of involving peers in a review of the researcher's work within the study allows the researcher's biases to be examined and his or her interpretations of the data to be explored. Debriefing with one's peers provides the researcher with a cathartic outlet, "thereby clearing the mind of emotions and feelings that may be clouding good judgement or preventing the emergence of sensible next steps" (p. 308). My research ethics board clearances allowed for the sharing of my data and its interpretations with the members of my academic PhD supervisory committee. Throughout the research process, debriefing sessions with my committee members took place often to discuss my interpretations of the data and decisions that were made with the community concerning the methodological process of the study. I looked forward to these sessions in person or

by telephone, as the input of my doctoral committee often served to lessen self-doubts about the methodological pathway and to verify that the data interpretations that I was making were congruent with the content of the transcription data.

Transferability. Lincoln and Guba (1985) defined transferability as the qualitative evaluative criterion that deals with the real applicability of the research to other peoples and/or settings, and is the equivalent measure of external validity that is used for quantitative research studies. Lincoln and Guba's (1985) stance on transferability as an evaluative criterion called upon me to address the query as to how I might determine the degree to which the findings of the current study could be applied to other Indigenous communities in Canada; in particular, to other reserve-based First Nations communities. I learned from First Nations Elders and from my review of First Nations related literature that each First Nation is unique in its language, culture, history, geography, economics, politics and in many other ways. Therefore, any efforts to make generalizations concerning my findings to other First Nations populations or other Indigenous peoples in Canada would be impossible, disrespectful and colonizing in nature.

Lincoln and Guba (1985) asserted that one cannot successfully address the external validity of qualitative research through generalizability as quantitative researchers are expected to do. However, if I can assure that a rich description of the client experience of the health centre has been produced, then, it will provide others with foundational knowledge about whether a transfer of the findings can be made to other populations. A key point made by Lincoln and Guba (1985) was that "If there is to be

transferability, the burden of proof lies less with the original investigator than with the person seeking to make an application elsewhere” (p. 298). In such a case, a person choosing to make a transfer of the findings needs to verify that there is empirical proof that the population to whom the findings are being transferred is contextually similar in many of the ways that I have stated in the previous paragraph and that cultural and related congruencies exist (Lincoln & Guba, 1985). The methods by which I assured a rich description of the client experience were described in detail earlier in this chapter concerning the multiple ways in which the community was informed about the study, the recruitment process, the use of purposeful, multi-variant sampling strategies, and the use of open-ended, semi-structured interview questions. I provided a detailed contextual description of the research setting.

Dependability. Lincoln and Guba (1985) stated that the determination of the dependability of a qualitative study is partly reliant on the degree to which the study can be deemed as credible. Dependability is strengthened by the use of multiple types of triangulation as have been discussed under the heading of credibility. The assessment of dependability involves asking how I can know for sure that if an interested party chose to replicate the study methodology with the same or a similar population that the same findings would result. To prepare for the possibility of a replication of the current study, I have maintained a detailed audit trail of all data and all decisions made in the process of data analysis and in the generation of study findings. This evidence has been preserved in my reflexive journal and field notes, and in the multiple, saved backup copies that sequentially recorded the development of my thematic analysis within the NVivo 8[®]. I

have retained electronic copies of all correspondence sent to participants and received from community members, transcript summaries, the original proposal and all documentation associated with research ethics approval and yearly monitoring.

Confirmability. In addressing the criterion of confirmability within qualitative research studies, Lincoln and Guba (1985) place the emphasis less on the neutrality and objectivity of the researcher and more upon the confirmability of the data. Essentially I need to ask myself whether or not the data and their associated findings represent the intended meanings of the health centre client experience as expressed by participants.

Lincoln and Guba (1985) stated that the criterion of confirmability can be best evaluated through a formal audit of both the processes and outcomes of the study. Such a study would ideally be conducted by an independent auditor (similar to the ways in which a financial auditor would examine a set of financial records). While a formal audit of the study has not taken place by an independent auditor, many elements of the study have undergone an informal auditing process through my ongoing dialogue with the research community concerning the steps taken during the research process, and through the sharing of data and its interpretation with individual participants and my PhD Supervisory Committee in both oral and written communication. I have submitted yearly reports to Research Ethics Boards of the McMaster University and the University of Windsor.

Ethics

Research ethics board approvals. Following the receipt of a written letter of approval from the chief of the community, I received ethics approval from the Hamilton

Health Sciences/McMaster University Health Sciences Research Ethics Board (REB) and from the University of Windsor's (REB) due to my relationship as an employee of that institution and its shared research memorandum of understanding with the First Nations community of focus.

Consents and security of research documentation. Throughout the research project the only individuals who had access to the interview audiotapes other than me were the members of my academic PhD Supervisory Committee and the project transcriptionist, none of whom were members of the researched community. All audio-tapes, transcribed interviews, my reflexive journal and any other confidential information related to the study were secured in a locked cabinet in accordance with REB policies. I was the only individual with access to the document that linked specific identifying data to a particular participant. All hardcopy data records will be destroyed within one year of the completion of the study by shredding, and in keeping with institutional policies and the principles of the research memorandum of understanding between the First Nations community and the University of Windsor.

The content of the research memorandum addressed the spirit of OCAP principles (Ownership, Control, Access and Possession) (Schnarch, 2004) and represented a mutually-agreed upon document that was consistent with the principles of participatory approaches to research. My adherence to this document and the CIHR Guidelines for Health Research Involving Aboriginal Peoples (Canadian Institutes for Health Research, 2007) assisted me in the ongoing demonstration of cross-cultural respect that is based upon genuine valuing of the research partnership between the community and me. I

followed (and continue to respect) the tenets of the more recently published *TCPS2* (Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans) document (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010). Chapter 9 of the *TCPS2* provided updated guidelines for me in relation to the conduct of research with First Nations groups specifically.

When preparing research reports, I recognized the importance of determining how to present the data and its interpretation accurately, yet in a way that would not jeopardize the confidentiality or identity of the study's participants (Speziale & Carpenter, 2003). In-depth interviews often contain rich data about a participant's life and experiences. Such data may include information concerning a participant's type of employment, age, and other demographics that together or separately could serve to identify the participant to another (Richards & Schwartz, 2002). The maintenance of participants' confidentiality and anonymity presented a particularly challenging ethical issue for me within the context of the researched First Nations community due to the close knit kinship ties and the relatively close living proximity of its residents.

To address this challenge, all participant volunteers read and signed a "Participant Consent to Participate in Research / Participant Information Form". Just prior to the commencement of their initial interview, each participant was asked to provide me with a self-assigned code name (or nickname) that would be used during the entire research process, whenever the participant was addressed verbally in audiotape recordings, and in all written research records, including interview transcripts and research dissemination

materials. However, it is important to point out that even with the stringent use of code names, it is practically impossible for the researcher to completely anonymize data even when great care is taken to remove or disguise specific demographics or other identifiers such as mannerisms of speech and details of participants' life contexts (Richards & Schwartz, 2002).

During my interview with the second participant who used the code name of Georgia, I learned that it is common in the researched community for many people to share a common rural mailbox. It is common for three to four households to share the same unsecured mailbox especially when only one driveway leads to all of the homes. While I had not yet mailed a summary of the first participant's interview transcript, my new knowledge of the shared mailboxes raised a concern in my mind regarding the possible inadvertent redirection of a client's mailed transcript to another household. In dialogue with the majority of participants, their preference was that I drop their interview summaries off to them directly whenever possible, in a sealed envelope, rather than sending them by post.

When follow-up interviews were conducted with each participant, any data that I had noted from each interviewee's initial interview transcript that might remotely serve to identify him/her to others was brought to the participant's attention for the option of disguise/substitution or omission. For example, in one transcript, a participant gave a detailed account of a sibling's illness. The unusual nature of the sibling's diagnosis could possibly have served to identify the participant to other community members if data from interviewee's shared story was used in dissemination reports. Therefore, I offered the

option for the participant to substitute the stated relationship status in the transcript from “sibling” to “relative” or “friend” and the nature of the diagnosis was made more generalized at the participant’s request. While a number of participants did request more generalized substitutions for a few terms in their transcripts (such as where they were raised or went to school), a few did not want any content within their transcripts anonymized in any way and their wishes were respected. One male and one female participant expressed to me that any efforts made to anonymize the wording of a transcript for them would serve as a form of minimization of their opportunity to freely give voice on their perspectives of the client experience of the health centre.

Summary

In this chapter I have discussed the methods used to complete the current study of the phenomenon related to the client experience at a First Nations health centre in Southern Ontario. I have described with considerable detail the steps taken in the formation of the research question, recruitment, determination of the participant sample, data collection and the process of data analysis that were conducted in collaboration with the researched community. I addressed van Manen’s emphasis on the notion of reflexive thinking and writing throughout the research process and the hermeneutic, circular movement within which I engaged with the data and in dialogue with the sample participants. I provided an essential discussion of ethical considerations related to the design and conduct of the current study through the application of the qualitative criteria for the evaluation of trustworthiness that were established by Lincoln and Guba (1985). My greatest challenge in conducting this study was to integrate and simultaneously apply

the Western philosophical ideals of Heidegger with the Indigenous philosophical writings of Professor Ermine within a participatory approach, while using a hermeneutic method of data analysis.

Chapter 6

Study Findings

I will begin this chapter of study findings with a brief description of the participants. Based upon the work of Max van Manen, I will then present the themes that resulted from my interpretation of the data concerning the meaning of the client experience at a health centre within a First Nations community. Heidegger's concepts of corporeality, relationality, spatiality and temporality will be addressed as they relate to the study findings.

Description of Participants

A total of 15 volunteers (6 males, 9 females) communicated interest in participating in the study during the recruitment phase, through direct contact with me or a member of the community advisory committee (CAC). Within the 15-member volunteer pool, there existed a larger portion of five individuals within the 60 years and over age group. By consensus, the CAC selected two female and two male volunteers within the 60 and over age group that represented the broadest range of other characteristics such as educational achievement, marital status and employment status. The third female in that age group was not interviewed as the saturation of data was reached prior to making contact with her for the administration of consents. She was informed of her option to contribute her stories and perspectives on the client experience to me through letter writing or another form of communication. I was unable to make subsequent contact with two of the other study volunteers with whom I had first made initial contact at the community health fair. Messages were conveyed to them regarding

their option to participate in the study through letter writing or other forms of communication. Therefore, 12 participants (7 females, 5 males) made up the final interview sample. Refer to the following table (Table 2 – Self-disclosed Demographic Profile of Participant Sample) which provides an overview of the participant sample composition.

Table 2

Self-disclosed Demographic Profile of Participant Sample

| Participant Characteristic | Sample Composition |
|---------------------------------------|---------------------|
| Male to Female Ratio | 5:7 (<i>n</i> =12) |
| Approximate Age Range: | |
| 18 – 29 years | 3 |
| 30 – 44 years | 3 |
| 45 – 59 years | 2 |
| 60 and over | 4 |
| Reported Marital Status: | |
| Single | 1 |
| Married or Common Law Union | 6 |
| Widowed, Separated or Divorced | 3 |
| Not disclosed | 2 |
| Highest Educational Level of Study: | |
| Grades 1 – 8 | 3 |
| High School | 3 |
| College or University | 4 |
| Skilled Trade Apprenticeship | 1 |
| Not disclosed | 1 |
| Experience of Parenthood: | |
| Have children under the age of 18 | 4 |
| Have children over the age of 18 | 4 |
| Not disclosed or reported no children | 4 |

| Participant Characteristic | Sample Composition |
|----------------------------|--------------------|
| Employment Status: | |
| Employed full or part time | 4 |
| Unemployed | 3 |
| Retired | 3 |
| Not disclosed | 2 |

Participants ranged in age from their early twenties to late eighties.

Approximately half of the participants were married or living in a common law relationship, while the remaining six lived alone or with other kin. Approximately two thirds of the sample spoke of their role as parents. Four participants were parents of young children and four other participants spoke of having children who had reached adult age. The highest level of educational study varied from grade three to university completion. In terms of employment status, one third of the sample was employed full or part time, while the remaining members of the sample were either unemployed, retired or did not disclose their employment status. Each participant self-assigned a code-name that would provide them with anonymity on all research documentation. The code names chosen by the female participants were Red Sky, Venom, Georgia, Daisy, White Wolf, Fern and Candy. Among the five male participants, the code names chosen were Hummingbird, Colt, Tips, Hucks and George.

Themes on the Meaning of Being a Client at the Health Centre

In van Manen’s interpretive approach to phenomenology, the researcher seeks to understand the meaning in the everyday experiences of a phenomenon by extracting themes from the data. According to van Manen (1997b) an essential theme “relates to a

notion” of the phenomenon being studied and that no single theme can fully “unlock the deep meaning, the full mystery, the enigmatic aspects of the experiential meaning of a notion.” (p. 88). He likened a theme to a “hermeneutic tool” (p. 170) that one can use to understand the universal meaning of a phenomenon.

Three primary themes were derived from the process of data analysis that included, (1) Health and being healthy; (2) I use the health centre; and (3) I don’t use the Health Centre. Refer to Table 3 below for a complete list of the themes and sub-themes that were derived from the data analysis.

Table 3 - List of Themes and Sub-themes

| List of Themes and Sub-themes | |
|----------------------------------|---|
| Primary | Themes Sub-themes |
| 1) Health and being healthy | <ul style="list-style-type: none"> a) Being in balance b) Having choices and being able to make them c) Being able to take care of myself and get the help I need d) Being able to care for and provide for others e) Eating right |
| 2) I use the health centre | <ul style="list-style-type: none"> a) For information about health b) For illness-related services c) To visit the traditional healer there |
| 3) I don’t use the health centre | <ul style="list-style-type: none"> a) The health centre doesn’t come to mind when I am sick or well b) I don’t know what they do/offer there c) I’m not comfortable there; it feels strange and unfamiliar d) I go to family, friends and Elders e) I try to heal myself |

The first primary theme stems from a sub-question of the research project that sought to gain an understanding of what the terms “health” or “being healthy” mean to First Nations community members. The remaining primary themes address the essence of the meaning of being a client at the health centre within the First Nations community of focus.

1) Health and being healthy. (*Minoyaawin*) The first interview question: “What does health or being healthy mean to you?” was used to begin the interview discussion in a non-threatening manner. My other main purpose in seeking responses to this question was to help me gain a better understanding of First Nations views and experiences around the concept of health. Five sub-themes associated with this overriding theme included: (a) being in balance (b) having choices and being able to make them; (c) being able to take care of myself and get the help I need; (d) being able to care for/provide for others; and (e) eating right.

1a) Being in balance. (Weweni bimaadzing) The concepts of harmony and balance of mind, body and spirit were central to participants’ discussions of what it means to be healthy. The words of Red Sky provided a predominant view of the concept of health as it relates to balance and harmony:

It’s a simple question but there’s no end to this. One of the things is being in balance ... Our bodies reflect the state of our spirit, the state of our emotions and my basic beliefs are spiritual ... that you have to start with the spirit. Which doesn’t mean that you can’t have simple solutions like a salve for a rash ... but basic health means being balanced in body mind and spirit.

Similar to Red Sky's position, Fern added that "*The wellbeing of your spirit encompasses culture, language, and ceremonies and all of those things are part of it*". Being healthy included the perception that one was in balance with one's surroundings which include people (family and community) and the earth. Colt likened this relationship as similar to the functioning of a successful hockey team, in that no one player stands alone. "They [the stronger players] would do what needed to be done ... if it meant skating with weaker players, they would do that and try to bring the best out of them."

1b) Having choices and being able to make them. (Yaaming waa zhichken, midash zhichken) Central to participants' views and experiences of being healthy was their valuing of self-determination, which related to the possession of appropriate knowledge and the power and freedom to make informed decisions about one's life course. Fern exemplified what many participants expressed in that being healthy encompasses:

... an awareness of the different areas of what health is ... and being able to maintain or to have some type of control over situations or circumstances that you're in ... to have some control over your own self; to decide on what's healthy, what's best for you ... and then to be able to get the information.

Daisy added the experience of being healthy required knowledge of available health services in the community and being able to access them.

1c) Being able to take care of myself and get the help I need. (Gnowendizyaanh, miinwaa naadmaagoonyaanh) For many participants, the experience of being healthy involved being self-sufficient; being able to care for oneself in an independent manner

and not being a burden to others. As a senior member of the community, Georgia viewed health as that which declines with age and stressed the importance of being able to secure the right kinds of assistance when needed to maintain her health and independence. For Georgia, health was aligned more with the ability to acquire help when needed rather than as a state in which disease is absent.

When you are young, you are healthier, you could go wherever you want to, do everything. But when you get sick or are unable to do the same things ... healthy I think is being able to ... if you need medication and stuff, to be able to get it. And if you troubled, I believe you need to be able to talk to someone about ... you know, your problems or whatever, and to be able to ... get help you know. And when you need help ... like in the home ... once in a while I will have extra money and get somebody to come in and help to clean. I got to get somebody to come and do my cupboards.

‘Help’ as a concept within this sub-theme was primarily associated with participants’ experiences related to having timely access to appropriate health services and personnel, and available, affordable transportation to get there. One half of the participants representing all age ranges, cited a lack of money and/or a lack of transportation resources as a major barrier to getting timely help for promoting their own health.

Georgia noted:

A lot of people don’t have rides, you know, and the money to pay anybody ... and they can’t get to the doctor or the health centre ... so they just don’t go to the

doctor then or whatever you know ... then their problem gets worse and they get sicker and sicker. I don't think that they can avoid a lot of that stuff.

A community leader recently informed me that the estimated year-round rate of unemployment was approximately 80%. High unemployment, the considerable distance required to travel to the health centre from more remote areas of the community, and rising gas prices were all cited by participants as factors that impeded the ability of many community members to get the help they needed to stay well or to cope effectively with illness.

Id) Being able to care for and provide for others. (Menmag kina weya) While some participants viewed being healthy as being able to get help when needed, others expressed that being healthy was measured by one's ability to provide help and care for others. Typical of this sentiment were the words expressed by White Wolf who stated:

To have good health, good mind, good spirit, you're able to help somebody. Somebody in need, whatever it may be. You'll be able to handle it. Because you are healthy, you're alert ... you are clear minded, and you are energized. You can handle what they have to talk to you about, sickness, health, ... And you have to be strong and healthy in order to help with these things. And that's what being healthy means to me. ...

This perspective infers one's obligation to promote the health of the collective. Conversely, the act of not caring for oneself may have direct and negative consequences for the health of family and community, both in the present and for future generations. Colt equated being healthy with being a good role model for others:

For me to be a real healthy person is ... you could be a role model, and you got to live it, you got to show it. It goes back to that whole “walk the walk, talk the talk”, and ... and anybody can talk the talk, but when people see you living and walking that, that way of life ... that to them its healthy because that creates change, that makes others want to do that, that makes others think, “Hey I can do this, he’s doing it”, and then that inspires them to, ask questions and look for help.

Hucks’ comment that being healthy was an essential requirement for being a “*good provider*” was representative of both male and female participants in the study.

Participants who had young children stated that being healthy was a requirement for them to be good parents.

1e) Eating right. (Giiyak wiisning) This sub-theme describes the meaning of eating right as central to the experience of being healthy. While some participants spoke briefly of the importance of regular exercise, avoidance of alcohol, illicit drugs, and cigarette smoking, the act of healthy eating was by far, the most commonly identified goal and essential component of physical health for most participants. A common view expressed was that one’s maintenance of a healthy state is necessary to stave off, or prevent the onset of diabetes, obesity and heart disease, which were all viewed as significant threats to the health of their community, across the lifespan. “Eating right” encompassed the acquisition of healthy foods, their proper storage, preparation and adequate consumption. George expressed a direct relationship between eating healthy and feeling good when he stated:

Being healthy is freedom from sickness or pain or aches. That's good health.

Being free and having the proper weight and all that and uh, I guess if you eat too much you don't feel good [chuckle] so that's what good health means to me, to live, to have proper diet and all that.

In her role as a young mother, Candy spoke of her maternal obligation to ensure that her children received the right kind of foods to stay healthy.

I try to make sure that my kids have a lot of food, ... that's one of ... my priorities is making sure that they have the ... right food because there is so much stuff in food these days. Like you don't know what is healthy. They may say it's healthy but what they put inside of cows and other food. It is not healthy so we try to make sure to get our vegetables and in the summertime we freeze them.

A few participants recalled times when knowing how to hunt, prepare and store healthy foods was common knowledge among the members of the community. They equated the ability to do this as not only central to being healthy, but also to basic human survival. Hucks recalled “*The leaner meats are good and they used to preserve foods too for the hard times. Dried the muskrats in sticks up in the attic ... they'd pull them down and boil them up and make soup*”. While older participants spoke of the act of healthy eating as an important skill, they expressed concern that the younger members of the community did not have adequate knowledge to make healthy food choices, or to prepare food in healthy ways. Hucks expressed his concern as follows:

Canning is another thing kids should be taught too. I mean when will we have worse times than now? [They] should be taught how to survive. They wouldn't

know how to survive if they had to go out and survive and get food for their family. They wouldn't know how.

The younger participants who all viewed healthy eating as the most important way to maintain health, were often quick to state that they did not have an adequate understanding of nutrition to make informed choices about healthy food choices and healthy food preparation. Fern related the importance of healthy eating to the high prevalence of diabetes among her extended family. She stated “*Food has always been stressful to me*”, and described her anxiety as stemming from her realization that she needs to eat healthy, but she felt that she lacked the knowledge needed to do so.

2) I use the health centre. (*Nda aabjitoon mnoyaangamig*) The second overriding theme addressed participants’ use of the health centre programs and services. The expressed perspectives and stories of the participants reflected three sub-themes of the client experience. They included accessing the health centre (a) for information about health; (b) for illness-related services; and (c) to visit the traditional healer there.

2a) For information about health. (*Waa zhi-kendimang mnomaadziwin*) Of the twelve participants who participated in the study, six stated that they called or visited the health centre to gain information about health in the form of one-to-one counselling, group classes or through the acquisition of print materials on health topics (specifically pamphlets, and the health centre newsletter). Tips stated that he found the health centre helpful when he needed information about diabetes prevention for himself and on attention deficit hyperactivity disorder for a relative.

Yeah, I spoke to the person at the health centre. She gave me some booklets, showed me how to eat right, do stuff that can prevent me from having sugar diabetes it's because I may be in the first stages of having it. Then I can do something healthy for uh ... like to prevent it ... where I can beat it before I even get it.

Colt defined his preference for the local prenatal classes at the health centre over similar prenatal classes offered in town, outside of their First Nations community. He recalled how the prenatal classes at the health centre were more informative and culturally attuned to First Nations ways of learning in the following story:

We started going to pre-natal, and we started learning about things, and [my wife] wanted to try a pre-natal class off reserve. And we went to the hospital in [town]. And eh ... I wasn't impressed because we went downstairs into a basement. We didn't have much windows, just some little wee small windows . . . A lot of what I learned on the island through the pre-natal here ... I guess I impressed the ladies that were [teaching the one in town] because they were asking us how did we know all this information? ... And it was just the fact that eh ... again, our people being visual learners, that we had a lot of visuals, we had the videos, we had the pictures [here].

Among participants who viewed the health centre as a source of health information, Venom stated that she often called the health centre staff to acquire educational materials to help her, her family and her friends cope with health and illness:

She [health centre staff member] got me information on the Tourettes Syndrome, the different things... You ask for certain information and you get it. ... plus I go [there] ... ah, they gave me ah ... what is it ... I think it's the Heart and Stroke Foundation? They gave me the [telephone] number and I called over there and ... and I got information from THEM. Like even for the diabetes, for the fibromyalgia, for the rheumatoid arthritis, and for the restless leg syndrome and all this kind of stuff. If they don't have the information, they'll give you the information how to GET the information [chuckle].

Venom viewed the health centre as her primary source of trusted health information that she could obtain quickly and with ease. The help she received from the health centre staff allowed her to share her newly acquired knowledge with others and this made her feel useful and a contributor to the health of others.

In addition to participants' expressed appreciation and use of health centre programs that offered prenatal and parenting classes, there was a commonly expressed appreciation for the on-site cooking classes and healthy eating classes that were offered occasionally in the kitchen at the health centre. These classes were recalled as enjoyable and informative by all age groups and across gender. Candy recalled how she enjoyed learning how to select and can tomatoes. Hucks fondly described his experience at a health centre cooking class as follows:

Well I learned stuff that I didn't know before, even the Chinese cooking, the different oils you can use for cooking. I mean you used to only use lard all the time. Olive oil for stir fry and some breads you can make. ... information that's ...

the foods just better for you and not to eat this white bread and all that all the time.

Participants recalled positive client experiences in their attendance at other types of information sessions provided by both health centre staff and visiting lecturers.

Venom recalled in particular, an outdoor class sponsored by the health centre where she was taken on a guided walk in the community by a visiting traditional healer. “*Medicine walks ... different places. [He] took us way down to uhm, I don’t remember what that road is called. It’s down back over there, the back settlement anyway*”.

Venom enjoyed being out of doors with other community members and it reminded her of the herbal knowledge that her mother and grandmother knew, but which she feared was slowly being lost as the older community members passed on. “My grandmother knew an herbal cure for tuberculosis” she said, “Everything we needed pretty well, we could get here [in our community]”.

2b) For illness-related services. (Aakziwnan yaaming e-zhinaadmaageng)

Despite the fact that the community’s health centre has a primary mandate to focus on health promotion and illness prevention, many participants envisioned the role of the health centre as primarily curative and disease-focused in nature. The main reason that the majority of the participants in the study stated that they had at some time been a client of the health centre was for the purpose of immunization as a child and/or for the immunization of their children. A few of the older participants frequented the health centre for diabetes monitoring services for blood glucose testing and for foot care that was provided by a visiting nurses organization.

Most of the participants indicated an awareness of the diabetes monitoring services provided by the health centre. Even if they were not frequent users of the health centre, the majority of participants mentioned appreciation of this service in the community. Georgia recalled “*I went to get my blood sugar checked [there]*”. Daisy stated her awareness of the diabetes monitoring program: *I know my [friend], uhm ... he has borderline diabetes. So they helped him out with one of those things that pokes your fingers ... a glucometer ... Yeah, so that’s ... I was happy to hear that they did that.* Venom noted that there was a monthly diabetes support group that was attended by a number of people that she knew.

2c) To visit the traditional healer there. (Wii-mbwaachag jiiskew-nini odi)

Some participants stated that their only use of the health centre was to access traditional healers who visited there from outside of the community. For White Wolf, the experience of being a client of the health centre related only to her experience in visiting traditional healers there, as evidenced in the following:

I just go [to the health centre] when there’s a guest coming in ... a healer, traditional healer that can help you in all areas of your life. Say if I’m kinda baffled about something and I’ve been dwelling on it quite a long time ... make confirmation, need an answer or ... I see that person just to see what’s in the back of my mind that will combine into one and then I know I’m on the right track and doing the right thing..... Sometimes I’ll do that.

The majority of the study participants however described their reliance on a blend of both Christian and First Nations spiritual traditions and as such, relied equally upon

“Western” (or “mainstream”) health care services and First Nations traditional medicine practices. Among this third group, many respondents referred to their frequent use of the health centre to make use of visiting traditional healers and herbalists. Colt’s comments were typical of this group:

I was asked to find out – what was my clan, my spirit name, colours and uh ... so I went out and asked ... and I set up an appointment, and I met with the healer there, and talked with him and ... and looked at where I was today ... and ... uh found out uh ... a lot about myself, and it wasn't so much stuff I didn't know, it just kind of helped me. It helped really bring things together ... connect the dots really.

3) I don't use the health centre. (Gaawii nda aabjitoosiin mnoyaa-gamig)

Among the participants, approximately one half stated that they used the health centre rarely or not at all. Five subthemes addressed participants’ varying perspectives and experiences regarding their lack of health centre patronage including (a) The health centre doesn't come to mind when I'm sick or well; (b) I don't know what they offer there; (c) I'm not comfortable there; it feels strange and unfamiliar, (e) I go to family, friends and Elders; and (f) I try to health myself.

3a) The health centre doesn't come to mind when I'm sick or well.

(Mnoyaangamig mikwendiziin pii-aakziyaanh maage mnomaadziyaanh) A number of the participants in all age groups expressed surprise at the content of the interview question that asked, “When you are well, what programs or services might you use at the health centre? The response “*Nothing, because I am well!*” offered by Candy was typical

of some participants who did not see the need to go to the health centre for any services that might be offered there. Similar to Candy's comment was that of another woman who stated "*The health centre? That's probably the last place I would think of*".

Some participants cited the health centre as a place they remembered going to as a child for immunization with a caregiver, but they had not used the health centre as an adult or they made visits there only on rare occasions. There were a number of reasons for this. Participants who had travelled out of the community for high school and/or employment tended to continue using health care services with which they had established a relationship outside of the community, even long after they had returned to their First Nations home community. For this group of respondents, it was common to drive an hour or more to see their care provider, even though they had access to similar care providers locally. Georgia stated, "*I don't know, it's ... I guess I feel more comfortable going to the doctor*". Fern, Colt, Venom and Candy all stated that there was a significant need for physicians in the community in that many residents were not registered with a family doctor. Among others, Candy's felt that the health centre should provide direct physician access to community members on site.

Well, I would go [to the health centre] if they had a doctor there, a regular doctor like you know maybe, maybe three/four doctors and you have your own doctor, you know that family doctor, pediatrician or you know something that for, for kids

3b) I don't know what they do/offer there. (Gikenmagsiig eshchigewaad mag)

Among the study participants who have not recently used the health centre, a commonly stated reason was that of not being aware of the kinds of programs and services were

offered. Daisy stated,

I don't know what they offer and ah I'm not real keen to find out. I just kind of don't really ... don't really know what they could offer me now. I just, but that's sort of a passive feeling ... you know what I mean? If I knew that they, they offered something that I, I could find useful, I would go back ... that's why. Yeah I would go back.

Candy stated: *“I really don't ask the Health Centre for any information or services because I think that they don't have the information I'm looking for. It's probably because I don't ask”*. Common to both Daisy's and Candy's comments was their reluctance to find out what services were offered by the health centre. Some of the younger participants in their twenties and early thirties, attributed their lack of knowledge of health centre services from living outside of the community during their teen years and returning only recently as adults. An expressed lack of knowledge about the health centre and its services and the passing of considerable time since their last visit may have contributed to feelings of separation and alienation from the health centre, its staff and programs.

Many of the participants, who were raised within the community, reported attending high school off-reserve and some sought post-secondary school employment or attended college or university at an even farther distance from their community. Their increased socialization in Western-dominated educational and employment settings may have led them to establish relationships with urban health care providers, thus further negating the felt need for access to services offered by the health centre. Fern stated

“That’s why I don’t know too much about the health centre because I don’t. I was brought up [outside of the community].”

3c) I’m not comfortable there; it feels strange and unfamiliar. (Gaawii bekaa wii-ninaam dabyaanh maa) Some participants stated that they avoided going to the health centre simply because they did not feel comfortable there. One expressed reason for this was based upon their concern that their confidentiality could be compromised by accessing certain services there. Daisy stated that she knew of the many prenatal services offered by the health centre and yet avoided going to the health centre for information because she did not want others to know that she and her husband were soon planning to have children.

[I] don’t want to go in and talk away to somebody, well I can say “What kind of prenatal stuff do you offer?” and then have them say “Oh are you pregnant?” I mean, not that they would, but I don’t want that ... like ... (chuckle) I ran into ... I don’t know ... You know if they had that on their website, you know, I would click around, but I don’t want to go in and talk to them, I just, and it’s not because of confidentiality, I just don’t want to [go there].

Others preferred to avoid the health centre because of kinship ties they had with members of the staff and did not want family members to know the reasons for their visits there.

Some participants who used the health centre on an infrequent basis stated that their avoidance of the health centre tended to stem from their memories of an uncomfortable experience of a past visit. Venom recalled an experience of discrimination

and stereotyping by a non-First Nations health care worker who was contracted to provide occasional foot care services at the health centre.

I took a family member there to see a foot doctor there because he is so flat-footed ... he needs orthotics ... that lady who came ... it was what she said. She said “All Natives have flat feet!” And I thought if there were certain Natives ... if they heard when she said that, they would have been seriously ... uh ... not hurt ... they would object seriously to it ... they would have been seriously offended by what she said. And I thought if she works with Natives, ahhhh ... she doesn't know us very well! That's what I thought of her.

The experience left her feeling only comfortable to visit the health centre when she was sure to meet with people with whom she was familiar and trusted.

Although no part of the interview question protocol addressed participant's spiritual practices specifically, many participants wove their spiritual beliefs into the interview discussion as a part of their expressed experience of being healthy.

Participants' comments in this area led me to understand that the community was made up of many spiritual traditions. A few of the participants chose to avoid the health centre as they felt uncomfortable with traditional healing activities as provided by a Traditional Healer. George in his strong devotion to his Christian faith expressed no tolerance for “Indian religion”. *“There's too much Indian stuff there. Yeah, being an Indian, I wouldn't associate with Indian beliefs, Indian religion and all that stuff ... I don't buy that because it'll affect my wellbeing as believing in Christ. It'll affect that”*. For George, the fact that traditional medicine practices are offered at the health centre made it an unsafe place for

him to be in terms of maintaining his spiritual and overall well-being. He added that “The best health centre they got in this community is the church”.

Familiarity and trust seemed to play a significant role in the stories participants recalled of their client experiences at the health centre. Red Sky explained to me the importance of familiarity and its place in First Nations communities when she stated: “*In a tribal society, everyone knows everyone else. They know their whole generation, their background, their grandparents, great-grandparents*”. Red Sky expressed that feelings of trust and comfort go hand-in-hand with one’s sense of familiarity with health care providers as well.

With respect to familiarity and trust in the First Nations client-provider relationship, Colt described the importance of feeling as if one has something in common with the health care provider. He did not always feel that he was familiar enough with some staff at the health centre and this would affect the choices he made about whether or not to access specific services there for himself and his family. In some cases Colt found it difficult to trust health centre care providers who appeared aloof or distanced themselves via their verbal and non-verbal behaviours. His comfort was diminished when he did not feel that he was perceived as equal to the health care provider.

It comes down to trust. And ... and if you ... if you believe the people that are in the building [health centre] are there, and are just as normal ... uh just as ... uh ... just people like you, then you’re going to give them your trust because you’re going to see there’s no difference.

Georgia added that how health care providers communicated with her, determined the level of trust that she placed in them.

I don't know, it's kind of an inner... sometimes it's an inner feeling that I get about a person that I find I don't, I don't ... trust that person. And I don't know, sometimes people can be so, oh I don't know ... "I want to do my job and get it done, that's it" ... you know. They don't take time to listen or to think "How can I help this person? What can I say that might make them feel better?" you know. And it's just so ... I don't know how to put it ... impersonal or something like.

Experiences of comfort, trust and familiarity with health centre staff all played an important role in decisions made by participants as to their likely use of particular services at the health centre.

Another factor that influenced client experiences of the health centre was evident in their descriptions of the building's structure and floor plan as non-inviting and "Western" or "mainstream" in nature. While some described the health centre as a "confusing place" because of all the structure's hallway and office partitions, others commented on the waiting room as a place that was unfriendly and cold – not in keeping with First Nations architecture which they described as more welcoming, more circular, inviting and inclusive in nature. Some expressed a particular dislike of the glass window that divided the waiting room from the health care providers whose offices were located behind it. Hucks stated, *"The health centre in our community looks just like the ones in town ... glass wicket and chairs in the waiting room ... nobody's talking ... I might as*

well go to town ... at least I get to see a doctor there". Colt described his experience as a client entering the health centre as unwelcoming and minimizing:

When you look to your right when you first walk in, there is a big glass window ... sure you can see the people on the other side, the files that are in there ... but you're speaking through a hole, you are given papers through that little slot, to ah ... and you 've got all of those chairs. Sure, they are comfortable, but the thing is, that you sit down, you look on the wall ... there is a little TV there for you to watch while you wait but there's ... times anyway, sometimes you don't get to go into that area behind those doors, those closed doors to see their office space, see them at work ... see their emotions, again that humanness that I guess we have, you don't get to see that ... you just kind of get there and you are in that little area and that's it.

For Colt, the health centre was not all that it could be. Its Western-like structure, glass windows, and closed doors seemed to say "keep out" and provided barriers that separated the workers from the clients as if in a class system – "us and them".

Among those who viewed the health centre as an uncomfortable and unfamiliar place, Red Sky stated:

There is something about the place that is, uhm ... it's not ours ... and we have no say over it. ... to me it's just one more alienating new innovation on the Rez. It's not ah ... all these programs have sprung up. We have no part of them, no say in them. Uhm, they spring up because if there's some silo, there's some pot of money that people hear about they uhm, write their proposals, they chase money, they set

up programs and all you get out of them are a few jobs for the people working there. Ah, the general population don't know what they are about and don't ... uhm, ah, it takes a long time for people to get rid of them or to get used to going to new programs that they don't ... they don't have a clue what they are there for.

Both of the quotations above speak to feelings of having a lack of input, ownership, control and belonging. In a culture where community consent, community ownership and the equality of its members are highly valued, these shared experiences from the client perspective helped me to understand how concepts such as familiarity and trust are nourished or lessened by the client's perceptions of inclusion and equality or exclusion and inequality respectively. Red Sky explained that *"There is not the sense of individualism [in our community] that there is in mainstream society. That's not our basic culture and there are still patterns of equality. A tribal society was perfectly equal ... the only true democracy that I can think of".*

3d) I go to family, friends and Elders. (Nda bgosenmaag enwemgig, nwijkiwenyig miinwaa getzijig) Many participants stated that when faced with a health challenge, their initial action would likely be to seek the advice of family, friends and/or Elders well before the advice of a health care provider. *"You have friends, who tell friends, who tell friends. You have to have a network, even on a Reserve."* Even complicated decisions about complex health care decisions such as the merits of taking chemotherapy for a diagnosis of cancer, or having gallbladder surgery are often made by group consensus that may involve both family members and trusted Elders of the community. Trusting in the familiar wisdom of family, friends and Elders is a normal part

of the First Nations ways of maintaining health and healing from illness. Candy gave an example of this:

If I think that I am getting a cold or something, then I go and talk to these old people and “Oh what can I take?” And they’ll hand me something to drink. “Drink this, it’ll, help you.” You know, just to flush out some of the bugs ... Anyway, I don’t go to the doctor.

Another reason cited by participants for the reliance upon friends, family and Elders was related to the fact that the health centre’s hours of operation for drop-in clients occurred primarily on weekdays and that nowhere within the community to seek nursing or medical services on evenings and weekends. Fern recalled a particularly stressful breast feeding experience associated with her newborn late one night, where she was in need of immediate lactation assessment and guidance. Given that she faced the prospect of an expected long wait at the nearest hospital emergency department several kilometers outside of the community, she turned to her aunt who was able to provide immediate reassurance and to support her with the care of her newborn through the night and weekend. In recalling her story, she stated,

I felt that I had the supports there and I, I just, I thought about what would happen if I were a teenage mom who didn’t have a partner, who didn’t ... I don’t know, maybe who, who didn’t have a family member to call or ... or and then I thought, would they call the Health Centre? Would they, I mean this was the weekend ... Like this was Friday night. And the [health centre] is closed and like who do I call and, and so it was my aunt and she doesn’t have a phone like I had,

I just put baby in her seat and I went over to see my aunt in the middle of the night and, and I thought, I don't know, I was just happy that my aunt was there and that I had the supports.

Candy spent much time with the Elders in her community and stated that much of what she learned about healthy eating resulted from conversations with them.

I learned how to check labels on foods. I learned how to check all the sugar and salt contents and the drinks and canned foods and boxed noodles that I feed my kids. That's no good, they [the Elders] say "put that back, go with something else different" ... so I actually learn more off of them than, than anything.

3e) I try to heal myself. (Nda kweji naandwidis) The final theme that described participant's perspectives and experiences concerning non-usage of the health centre, related to their preference for self-healing activities. Self-healing activities stemmed both from participants' preferences to be independent and self-sufficient concerning health maintenance, as well as from a desire to maintain privacy concerning their health status. Additionally, one's reliance on self-healing activities was a strategy to avoid the need for Western allopathic approaches to health and illness. By engaging in activities to solve a health challenge first by oneself, one had the potential to avoid the need to seek help from others. Two senior respondents commented that discussing one's health or illness with a stranger, or even sometimes with family members is not always consistent with First Nations ways of relating. Red Sky stated "Native people don't complain". She said that this may in part be related to their experiences of the residential school system 'where one only spoke when one was asked to and where one was often punished for speaking

out of turn’. “I keep my problems to myself generally because no one wants to hear about them”. In particular, Venom stated:

Don't talk to people about how you feel because nobody wants to h-e-a-rrrrr you [spoken in a deep mocking tone] Like, Keep quiet! Shut up! Don't say nothing! Don't even talk about your... like if you have a problem ... like if you're being abused and stuff like that, you don't tell anybody. What happens behind closed doors, it's nobody's business. And it just ... it just kind ah gets into one's personal beliefs and I think that a lot of people, like when they hear you talk about your problems, they don't want to hear it.

Many of the younger participants preferred to be given pamphlets, watch the television, or use the Internet to find information on exercise, healthy eating, and diseases that affected members of their families. Daisy's comments were highly representative of this group of participants who preferred to learn about health in ways which were independent of health care providers:

I like uhm I like a lot of pamphlets. I like reading, I like reading my information. I like just grabbing it, show me ... show me how... where something is that I can read more about it. I like to take my stuff home and read it so I like ... I'd rather do that than really sit and talk to people.

Hucks relied on the television, the health centre newsletter and other print materials as his main sources of health information for self-healing and health maintenance.

Ah ... a lot of times, I watch TV, the [local] stations I ... the health works programs and I pick up different information from there about things on how you

can make yourself healthy, exercise and the right foods to eat. Like I heard one time that cinnamon helps fight diabetes and so my friends my age are already passed away and some of them were leaner than me and they had partial heart attacks. So I have been like a sponge in the last ten, fifteen years ... trying to absorb all this that pertains to me.

Another area where participants engaged heavily in self-healing activities was through the use of over-the-counter (OTC) medications, herbal remedies and other traditional healing practices. George advised me to: *“Take an aspirin first. [chuckle]. Because aspirin has a lot of curing and uh aspirin, there’s, there’s a lot of things that they don’t even know about aspirin. It does a lot of things. It’s not miracle drug but it’s pretty close”*. Like George, Candy turned to OTC medications for herself, whereas she would be more likely to take her children to a health care provider: *“When I’m ... when I feel sick ... most of the time, I just take medicine that’s off the shelves that’s in the stores. I just read the label”*.

I was informed by a number of participants that there is a growing resurgence and reliance on the use of traditional herbs and other traditional healing practices across all age groups in their community. Many participants spoke of their use of traditional herbs in the form of teas, salves, poultices, baths and related preparations to assist in both health promotion and self-healing. Some attended talks at the health centre and went on medicine walks around the community when offered by visiting traditional healers and herbalists. Others relied on the knowledge of Elders in the community or studied herbal

preparations through other means. White Wolf who continually aspired to live a traditional life described how she harvested traditional medicines.

I can be walkin' and lookin' and then that plant will stick out like a sore thumb. It's like "Here I am". It's like tryin' to get my attention. So then I go to the tallest of those plants that wants me to pick it and if it will help me I offer it Samma [Sacred Tobacco]... Thank you for its help. I offer it tobacco ... you go to the plant that is like in the teenager stage cause they're the strongest at ... they're thriving. They're just young and they're strong. So that's, that's what I would pick. And I'd give this tobacco and give it thanks for what it's going to do for me.

The majority of the participants referred to the use of some traditional First Nations medicines in their self-healing repertoires and stated that they would like to have more access to trustworthy information within their community on the use of herbal preparations. They interpreted the changing role of the health centre as supporting the resurgence of local interest in herbal preparations to ensure that community members learned the correct and safest ways to harvest, store and prepare herbal based medicines from their environment for personal use.

Informational Data Summary: Participants' Vision of an Ideal Health Centre

Early in discussions with the community regarding the research proposal, some representatives expressed their common belief that the community's participation in the research process would be as important to the community as the outcomes of the study. While they expressed a primary interest in gaining an understanding of the meaning of the First Nations client experience at their health centre, they were hopeful that the study

would provide community members with an opportunity to have their voice heard (and recorded) in the form of specific recommendations for the improvement of the health centre. The statements below that were expressed by Colt at the end of his first interview provide one example of how the use of interviews in this study raised his awareness concerning his own views on health and the health centre and furthered his intent to discuss his personal vision of the health centre with other community members.

So you know eh ... the interview tonight was ... was great. It really helped me. It helped me realize exactly what we have here, and eh ... It's a health centre that's a link to health services within our own community, in our neighbourhood really, in our own yard ... I want to chat it up with ... with friends or family ... what our health centre really means to us. Because I mean, I myself ... take it for granted at times, and I look at it. And just talking tonight, it's really made me realize that it is ... we are lucky to have the centre there because there are communities that don't have that ... that have to have people [health care providers] come in.

Throughout the interview process, participants voiced their ideas regarding how they might change the health centre if it were in their power to do so. The participants' recommendations concerning the health centre were each coded in the NVivo 8[®] software program in a separate data section from the theme tree. While not considered as thematic interpretations of the First Nations client experience at the health centre, the participants' collective vision for modification of the health centre was important to include within my dissertation content in terms of its potential value for, and use by the researched community for further dialogue and health service planning.

For these reasons, I have included a table that begins on the following and summarizes their recommendations (refer to Table 4 – Summary of the Participant’s Common Vision of an Ideal Health Centre). Within Table 4, the first column refers to participants’ recommendations concerning people that provide (or could provide) services at the health centre. The second column refers to participants’ suggestions for modification of currently-offered health centre programs and services and the addition of new ones. The third column addresses participants’ expressed ideas concerning ways to improve the existing design/structure of the health centre’s physical space and the addition of tangible resources/equipment to make the space more useful, culturally appropriate and/or health promoting. It is important to point out that some of the recommendations for change that were made by study participants may in fact already have been addressed by the health centre without the knowledge of the participant or may have taken place since the completion of data collection. It is important to note that the recommendations contained within the table represent commonly expressed notions of an ideal health centre that were expressed among the study’s participants and cannot be assumed to represent the views of all 12 participants.

Table 4

Summary of the Participants’ Common Vision of an Ideal Health Centre

| Table Summary of the Participants’ Common Vision of an Ideal Health Centre | | |
|---|--|--|
| People | Programs | Place |
| <p>1) Staff are healthy, well-rested and free of caregiver burnout</p> <p>2) Visiting health care providers demonstrate at least a basic understanding of First Nations culture</p> <p>3) Traditional healers visit the health centre on a regular basis and there are ample appointment times available to meet community demand</p> <p>4) Community Elders are utilized within health programs for the sharing of their expertise and life experiences in areas such as parenting, childbirth, healthy food preparation, hunting and instruction on outdoor survival skills</p> <p>5) Health care providers such as</p> | <p>1) The health centre provides services to promote health and cure illness within our community. There is no separation of service mandates between health promotion/illness prevention and the diagnosis and treatment of, and recovery from diseases that we experience.</p> <p>2) Community education “talks” take place on a regular basis that are:</p> <p>a) Well publicized</p> <p>b) Free-of-charge</p> <p>c) Led by experts in the field</p> <p>d) Aimed at various ages including children</p> <p>e) Offered at the health centre or at an alternate location within the community</p> <p>f) Address topics of community interest, concern and focus such as:</p> <p>i) Traditional medicines (including healing philosophies, ‘medicine walks’ and the safe use of herbs)</p> <p>ii) Diseases associated with aging and those that affect the eyes,</p> | <p>1) The First Nations health centre occupies a building in which the design and materials are culturally relevant and inviting such as:</p> <p>a) Circular or octagonal floor plan (i.e., more symbolically aligned with First Nations views of health and healing such as with the medicine wheel)</p> <p>b) Made of safe, natural products</p> <p>c) Adaptable in shape to suit a variety of community needs for assembly (e.g.: open concept, but modifiable to meet needs for individual client confidentiality)</p> <p>d) Includes both indoor and outdoor spaces for assembly</p> <p>e) Places less formal structural barriers between clients</p> |

| Table Summary of the Participants' Common Vision of an Ideal Health Centre | | |
|--|--|--|
| People | Programs | Place |
| <p>community health representatives, dentists, family physicians, medical specialists, nurses, pharmacists psychologists, and traditional herbalists all deliver services at the health centre</p> <p>6) A variety of other health care consultants such as nutritionists, fitness trainers, massage therapists, yoga and tai chi instructors visit the health centre on a regular basis to provide individual and group instruction</p> <p>7) The health centre staff maintain a strong, visible presence in the community at events that are held outside the structural confines of the health centre</p> <p>8) There are increased opportunities for community members (particularly those who are elderly and/or physically</p> | <p>heart, lungs, kidney, nervous system, Type I and Type II diabetes, and cancer (such as breast, bowel and prostate cancers)</p> <p>iii) Parenting issues and skills development</p> <p>iv) Childhood learning disorders, (e.g.: such as generalized learning problems, attention deficit hyperactivity disorder, obsessive defiant disorder, and Tourette's syndrome),</p> <p>v) Healthy food harvesting and preparation (including gardening, cooking, freezing and canning)</p> <p>vi) Safe use of fitness equipment including weight training equipment</p> <p>vii) More regular contests and organized group activities focusing on healthy weight loss, jogging and walking</p> <p>viii) Water safety classes</p> <p>3) Self-teaching educational materials are available for community members that:</p> <p>a) Address a variety of ages</p> | <p>and staff (e.g. less dividing walls, and glass windows.</p> <p>2) The health centre has ample structural resources to promote community member engagement in traditional and mainstream wellness activities and assist those coping with illness to get better such as:</p> <p>a) An exercise room with basic fitness equipment that can be used by both young and old</p> <p>b) Infra-red sauna for those unable to use sweat lodges</p> <p>c) A year-round indoor swimming pool for recreational swimming, aqua-fitness and water safety classes</p> <p>d) More rooms accessible for regular community-generated healing circles (e.g. for groups of men, women, teens,</p> |

| Table Summary of the Participants' Common Vision of an Ideal Health Centre | | |
|---|--|--|
| People | Programs | Place |
| <p>confined to their homes) to meet with health centre staff at locations apart from the health centre complex (referred to by participants as greater '<i>staff outreach activities</i>' for health promotion and illness/injury prevention.</p> | <p>b) Address a variety of learning needs and capabilities (in terms of the depth of information provided)</p> <p>c) Are provided in a variety of media formats such as:</p> <ul style="list-style-type: none"> i) Written pamphlets ii) Trusted internet links that provide access to provincial and national health organizations from a health centre-managed website iii) Audio and video library of interesting health topics to borrow or view on-line <p>4) Periodic community forums are held with the health committee and health centre staff to brainstorm about health centre services and events that serve to promote dialogue about among community members</p> <p>5) There is greater communication and related program linkages between the health centre programs and other community departments such as the public school, youth centre, social services the senior's residence and the library</p> <p>6) Staff programming is in</p> | <p>young mothers, parents, Elders, caregivers, etc.)</p> <p>3) Near the health centre, there is an outdoor partially-covered space where the community can come together to socialize, hold ceremonies and celebrations</p> <p>4) The health centre has signage in the main entrance area (public areas) which identifies staff by name and the programs in which they provide services</p> <p>5) There is a suggestion box at the entrance where clients can submit their ideas concerning the health centre.</p> <p>6) The information technology infrastructure of the health centre includes a dedicated website which is password protected so that only community members can access selected webpages. A community member</p> |

| Table Summary of the Participants' Common Vision of an Ideal Health Centre | | |
|--|---|---|
| People | Programs | Place |
| | <p>place that provides ongoing 'care' for staff who may be at risk for burnout and related illnesses (due to the community's ongoing dependence upon them for health care service provision in a close knit community in which many of the staff members reside).</p> <p>7) There are health programs that are offered specifically for men by men on issues of interest to them such as:</p> <ul style="list-style-type: none"> a) Being a father, role model, 'warrior' and 'hunter' b) Maintenance of healthy relationships c) Male diseases like prostate cancer <p>8) There are different types of classes/programs that focus on mental and spiritual aspects of health and illness that are either peer led (by Elders) or by health care providers. The design and content of these programs has had much input from community members and address issues such as depression, anxiety and grief</p> <p>9) The health centre provides access to an on-call service that provides access to a designated health care</p> | <p>can go to the website to:</p> <ul style="list-style-type: none"> a) View an up-to-date calendar of events health centre events, b) Learn about all of the programs offered at the health centre and the staff that provide them. c) Link to trustworthy health services and health information sources outside of the community that have been evaluated and designated as "safe to use" by the health centre staff. d) Find out about health promotion events and traditional healers that may be visiting nearby health centres e) Pose general health-related questions by email to specific health centre staff or a designated health care provider via email f) Post healthy |

| Table Summary of the Participants' Common Vision of an Ideal Health Centre | | |
|--|---|--|
| People | Programs | Place |
| | provider that provides local, culturally-congruent health (non-emergency) health care advice and referral for community members regarding day-to-day health issues (e.g. breastfeeding challenges, parenting issues, diabetes challenges, caring for elderly family members). | recipes or other ideas for community reading and discussion (like a virtual bulletin board). |

People. A number of participants expressed much appreciation for the compassion, hard work and knowledge that is provided by staff of the health centre within their community. The same participants expressed genuine concern for the overall health and well-being of the staff of the health centre in light of the constant demand for their services that extended beyond the Monday to Friday formal work schedule. This related to their expressed belief that one needs be healthy in order to effectively help others. A number of participants concluded that their observed changes in health centre personnel over time were directly related to staff burnout and the additional stresses that staff members face as individuals living within the same community in which they practice. Their perceived ability to establish long-term relationships with the health centre staff was a key factor for participants in their ability to feel a sense of familiarity, comfort and trust about their client experience there. Such feelings of familiarity, comfort and trust factored directly in their choices as to whether to seek services at the health centre or outside of the community.

Cultural competency was a significant concern among community members especially in relation to health care providers who provided service as outsiders to the community. Some interviewees stated that diversity training that specifically pertains to First Nations should be required for all health care providers *prior* to their introduction to the community's health centre.

A resurgence in community members' interests in traditional healing practices was voiced by the majority of participants, many of whom admittedly combined both mainstream and traditional approaches to personal health maintenance and illness/injury prevention. Of those who wished to access the services of traditional healers within the researched community, the majority reported that they often encountered challenges in securing an available appointment. It was the expressed belief of the majority of participants that the health centre should provide access to a broad range of health care practitioners within the community. Some participants reported that they did not understand why other smaller First Nations communities to which they had travelled, provided greater client access to health care providers such as dentists, nurse practitioners, physicians, pharmacists and related disciplines within the community health centre structures. Participants emphasized that what they wanted was the choice as to whether to access mainstream practitioners within or outside the community when at the time of data collection, there was no opportunity to access such services within the community on a regular basis.

Programs. While approximately half of the participants reported that they used the health centre in some capacity, the majority of those who did not use services

provided by the health centre felt that they would go to the health centre if they knew of services that they would find useful there. Many interviewees expressed that a health centre in their community should serve both as a centre for health promotion as well as a medical clinic for the diagnosis and treatment of illness. As such, they did not understand why they could not access a physician or nurse practitioner at their health centre on a daily basis for diagnosis and treatment of disease (beyond the existing services that address mental health and substance abuse).

The types of services and programs envisioned by participants are listed in Table 4. It is important to note that while many viewed a First Nations health centre as the centre of a wheel or a ‘heart of the community’ from which a variety of traditional and mainstream services could be accessed, they did not expect that the health centre alone would meet all of one’s health care needs. This was reflected in their vision of a health centre-authored and -managed Internet website, that would provide community members with trustworthy virtual linkages to health and illness-related organizations and services outside of the community. Participants valued greater linkages between the health centre and departments and services within their community (i.e., school, social services, library, arena). Some stated that ‘silo nature’ federal funding for a variety of service areas within First Nations communities either leads to wasted duplication of service and/or a lack of coordination of services or more often, a general lack of community service coordination overall.

Place. Many participants who reported infrequent or no use of health centre services commented that the health centre as a physical structure looked very “non-

native”. Terms used by some participants to describe the health centre’s physical space and design included “uninviting”, “not friendly”, “foreign” and “unfamiliar”. Others stated that its design created artificial boundaries between staff and the community and they interpreted the structure as “not ours” and more mainstream. Some took particular exception to the design of the waiting room seating and the use of a glass window that separated reception from waiting clients. Some participants described the core of the structure as having too many internal walls and hallways that made it seem “disorienting” and a confusing place in which to find one’s way. Others felt that the health centre as a central focus of the community should be allotted both inside and outside spaces within its land area to allow substantial numbers of community members to gather for health and social events that celebrate and promote the health of the community.

One particular idea that was supported by the majority of participants across all age groups was the community’s need for the provision of an adequate information technology infrastructure that would provide community members with reliable access to a comprehensive health centre informational website. It was interesting that those who reported no recent use of the health centre said that if a health centre website was available, they would use health-related websites that had been recommended by health centre staff, over any websites they might find on their own. Secondly, many who reported being generally unaware of services offered at the health centre, stated that they would go to a health centre website if available, to learn more about the services offered there. At the same time, they were not interested in going to the health centre building

for the purposes of learning what was offered there. This was particularly voiced among younger health participants who were avid users of the Internet.

Reflexive Notions on Heidegger’s Temporality, Spatiality, Corporeality and Relationality

Heidegger stated that “What hermeneutics is really meant to achieve is not merely taking cognizance of something and having knowledge about it, but rather an existential knowing” (1938, p. 14) . That is, to know and understand the common experiences of a phenomenon, but also the unique experience that shape what we know about a topic of study. In his application of Heidegger’s philosophy to data interpretation, van Manen identified “four fundamental existentials of spatiality, corporeality, temporality and relationality” through which human beings experience the lifeworld (1997b, p. 102). According to van Manen, each of these notions can be described individually, but cannot be separated from one another in terms of a human experience. In other words, one’s being in the world involves a simultaneous experience of “lived space”, “lived body”, “lived time” and “lived other” (pp. 102-105). In this section, I will provide examples from the current study that illustrate the relationship of Heidegger’s four existential elements to the phenomenon of the client experience of First Nations health centre.

Temporality. According to van Manen (1997b), temporality or “lived time” (p. 104) within Heidegger’s philosophy did not relate to time as set by a clock, but rather as time lived subjectively or felt time. He used the example that when one is actively engaged in an enjoyable activity, time seems to go by quickly, whereas when one is waiting

anxiously for something to take place quickly, time seems to slow down. In the words of van Manen, “The temporal dimensions of past, present, and future constitute the horizons of a person’s temporal landscape”(1997b, p. 104). All experience is rooted in time and therefore time gives meaning to human experience. Fern favourably recalled a health provider’s visit to her home in relation to time: *“The visit seemed an okay time length, like it wasn’t long, too long or too short”*.

Time was an important element in participants’ discussions of health and their client experiences of the health centre. Hucks viewed the health of the community in relation to time passing:

A lot a years ago things were tougher than they are now. And you had to literally be physical to provide for your family and [our community] was like a giant grocery store years ago ... hunting, fishing, trapping. The fur trade is gone and none of the men hardly exercise anymore like they used to [in the]... fall winter and spring.

Both Georgia and White Wolf described a positive health experience as one in which the health care provider “takes time” to listen. They both stated that in the Western way of providing health care, often, not enough time is given at the beginning of the health care interaction to place the client at ease and inquire as to how they are doing before entering into specific discussion of personal health issues.

Spatiality. Spatiality, also termed by van Manen as “felt space” (1997b, p. 102) is often less directly reflected upon in participants’ descriptions of the care environment, but is recognized in the way one feels about the space in which an experience takes place.

This was particularly evident in the way in which participants described their level of felt comfort or discomfort when visiting the health centre. Red Sky felt uncomfortable in the hallways of the health centre in that the space seemed disorienting and confusing to her. She stated that she found this to be common to many of the buildings within the community that were designed more on a Western or mainstream floor plan; less open and full of walled barriers between workers and community members. van Manen stated that in some instances, the way one perceives one's environment, directly affects what one becomes in that environment. For those clients who saw the health centre as unfamiliar or strange to them, they felt as strangers within it.

Colt thought that community members need to feel ownership of the health centre; that it is "ours". He said that if the health centre does not feel inviting, then it does not feel as if it is "our health centre". George saw the space "back, behind the desk" (referring to the reception desk of the health centre) as "a place of power"; power that can be used positively or negatively in terms of the establishment of healing relationships with community members as clients. The health centre's reception desk with its glass window at the health centre was mentioned by a number of participants as a dividing line. Colt stated that it divided "them" (the staff) from "us" the community and that one was either "in" or "out". While the distance between the front desk and the offices of staff could be objectively measured in yards, the emotional and social distance between clients and staff seemed much farther to many participants.

Corporeality and Relationality. The terms corporeality and relationality are referred to by van Manen (1997a) as "lived body" and "lived other" respectively (pp.

103-104). From van Manen's perspective, one experiences the world through one's body and it is through the body that we interact with others. Our experience of being in the world causes us to simultaneously reveal and conceal aspects of ourselves both consciously and unconsciously when we interact with another. Many participants recalled their client experiences of the health centre as positive or negative largely in relation to how they reacted to, or were treated by health care providers. Georgia rarely used the health centre and met the majority of her health care needs through her family doctor in the nearby town. It was important for her to know her care provider well and to know what to expect when she sought health care there. She avoided the health centre and after-hours clinics because for her, there was less predictability in regard to the persons with whom she might interact.

Sometimes people can be so, oh I don't know ... "I want to do my job and get it done, that's it" ... you know. They don't take time to listen or to think "How can I help this person? What can I say that might make them feel better?" you know. And it's just so ... I don't know how to put it ... impersonal or something like. I go to my family doctor for all of my health needs. I have known him and his wife for a long time.

Venom stated that regardless of where she accesses health care services, the way in which she feels intuitively about a health care provider has a direct impact on her degree of comfort within the interaction and upon whether or not she would access that service and service provider again: "I don't know, it's kind of an inner ... sometimes it's an inner feeling that I get about a person that I find I don't, I don't ... trust that person".

Colt stated that many people in his community are not likely to go to the health centre unless they feel that they have something in common with the care provider; something that makes them familiar and knowable at some level:

If [the health care provider] shares with them ... uhm ... and kind of, I guess not fully self-disclose everything about their life, but if they just kind of ... if there's similarities there, ... then yeah, they're going to really ... accept them. They're going to learn Wow! Uhm That new nurse I didn't know she ... she' got three kids. I didn't know that. You know, wow she's got to go home from here and she's going to go home to the same thing I've got ..got to cook supper, got to pick up toys, probably stepped on toys. "She goes through the same thing I do, so that helps.

In this study, participants' stories were heavily context-laden with detail included about client's memories and perceptions of lived time, lived space, lived body and lived other in relation to the client experience. This is congruent with what is known in the literature in that First Nations peoples experience health and illness deeply within, and inseparable from the context of everyday life and these details of their lives serve to empower or to disempower them in terms of their ability to maintain health.

Summary

The data yielded a rich description of the First Nations client experience associated with the health centre within the community of focus. From my interpretation of this data using van Manen's method of data analysis, three overriding themes were

derived that included: (1) Health and being healthy; (2) I use the health centre; and (3) I don't use the Health Centre.

The notion of health resonated strongly with being in balance in mind, body and spirit. Being healthy involved having a sense of control and the ability to make informed choices about one's health and life in general. The experience of being healthy was viewed as essential to one's ability to take care of oneself and to provide for others. The act of eating right that including knowing how to select and prepare healthy foods was viewed as a central skill in order to be healthy.

Those who viewed themselves as active clients of the health centre, the health centre was important to them as a place to gather information on health and illness, and as a place to access specific health care services such as prenatal care and nutritional counselling and specialized health care providers such as traditional healers and diabetes educators. For those who used the health centre on a frequent basis, it was a place that they returned to because of positive past experiences and/or because they felt comfortable accessing services there as a local (within their First Nations community) and a culturally familiar health service.

Among those participants who stated that they used the health centre rarely or not at all, a variety of sub themes were drawn from their stated stories and experiences in relation to the health centre. For some, the health centre was simply not an alternative that they considered accessing when they were sick or well. Among this group, some participants stated that they did use the health centre services because they really did not know what services were offered there either because they had not inquired, or because

they had moved recently back to the community with pre-established health care provider relationships outside of the community. For others, the lack of a physician presence at the health centre was their justification for seeking health services outside of the community where physician access was available.

A selection of both young and older members of the community chose not to access the health centre due to a perceived low level of comfort and familiarity with the building structure/design, the personnel, and/or the service choices offered. Some participants avoided the health centre as they preferred to access services outside the community where they were less likely to be known on a personal level by health care providers. A variety of young and older participants stated that they generally avoided services both at the health centre and elsewhere as they relied primarily on the health advice of their family, friends, Elders, or the media for self-care of both health and illness related issues. In such cases their expressed lack of experience as a client of the health centre resulted either from their perception of the health centre as a place where one goes only when one is sick or because they did not perceive the health centre as offering any services that were of interest or need to them.

It is important to note that among those who viewed themselves as infrequent users of the health centre, the majority of participants indicated that if changes could be made to the health centre, particularly to the types of services offered, and/or if they became aware of services that were more in line with their personal needs and preferences, they would definitely use the health centre more often. A number of participants expressed that a health centre should be like the ‘heart’ of their community or

like the central spoke in a wheel. Whereas the notion of health was expressed by many participants as a balance of mind, body and spirit within the individual, family and community, the ideal First Nations health centre was viewed as the pivotal structure and community gathering place within which health and all resources and activities that foster health should be primarily associated.

Chapter 7

Discussion

The purpose of the study was to gain an understanding of the meaning of the client experience at a health centre within a First Nations community in southern Ontario with a primary health service mandate focusing on health promotion and illness and injury prevention. The philosophical foundations of this study included the work of Cree scholar Professor Ermine and the Western philosopher Martin Heidegger. The methodological approaches used in this study included hermeneutic phenomenology, the data analysis method of Max van Manen (1997b) and participatory processes. In this chapter I provide recommendations for change in First Nations health services provision based upon the findings of the study and propose implications for nursing practice, education, research and policy. The chapter also includes a summary discussion of recommendations that were proposed by study participants in relation to their collective vision of an ideal health centre within their First Nations community.

Unique Contributions of Study Findings to Nursing

A small number of published research studies in North America have examined Indigenous client experiences in relation to mainstream (Western) health care settings such as hospitals (e.g.: Baker & Daigle, 2000; Browne, 2007; Guadagnolo et al., 2009) and urban health clinics (e.g.: Bucharski, Reutter, & Olilvie, 2006). This research project was the first of its kind to study the client perspectives of First Nations adults in relation to their experiences at a health centre with a primary service mandate of health promotion and illness/injury prevention located within their own community. The majority of

studies in North America have examined female Indigenous clients' perspectives or have employed samples with minimal male representation. The results of this study yield new insights into both female and male participants' perspectives of their client experiences at a health centre within their own community.

Discussion of Findings

In this section I will discuss the findings of the current study by comparing them to previous, relevant studies (1990-2012) in Canada, the United States of America, Australia and New Zealand. Relevant studies of client perspectives and experiences of health services in Australia and New Zealand are scarce, but I have included reference to the few relevant studies that were found. I will discuss the findings of the current study that contribute new knowledge to the body of literature and understanding of the First Nations client experience. My review in Chapter 2 of the North American research literature on Indigenous client experiences of health services yielded knowledge concerning Indigenous peoples expressed needs to: 1) be respected and understood; 2) feel comfortable; and 3) be in control within interactions with health care providers. The analysis of data from the current study yielded three overriding essential themes: 1) health and being healthy; 2) I use the health centre; and 3) I don't use the health centre. A summary of non-thematic data obtained from the study provided a common participant vision of an ideal health centre within the First Nations community of focus.

Health and being healthy. It was important for me to gain a basic understanding of First Nations perspectives on the concepts of health and being healthy. The initial question which asked participants what health or being healthy meant to them served as a

non-invasive question upon which to begin our conversations about the topic of health. The participants' responses to this question helped me to gain an understanding of the context within which health and illness are experienced in their First Nations community. Most participants spoke more about the nature of being healthy rather than trying to define health as a stand-alone concept, the absence of disease or an end goal. The participants' collective view of being healthy was described as a fluctuating state of being that varied in relation to one's level of balance in mind, body and spirit. This view of being healthy was expressed by Native American participants in the study by Dodgson and Struthers (2005).

The wholistic view of health as expressed by the participants in the current study compared similarly to the findings of Graham and Stamler (2010). In both studies, participants did not view health solely as an individual experience, but rather as something that was intertwined with the perceived health of one's community. In their study of the meaning of health among youth and adult members of a Northern Manitoba First Nations community, Isaak and Marchessault (2008) stated that participants defined health by making reference to the Medicine Wheel, in that being healthy required addressing mental, emotional, spiritual and physical health aspects of being. Cohen (1998) noted that in the traditional Native American Medicine, health is defined in ways similar to most Indigenous cultures around the world as relating to the 'whole'. Within such a wholistic view one needs to bring all aspects that make up human existence into balance or harmony in order to achieve health. Arnold and Bruce (2005) noted however that while there may be common themes in the ways in which different First Nations

groups define health and being healthy, several contextual factors influence the way in which members of a particular First Nation view health as a concept. These factors include colonization, past experiences with Western and Indigenous healing systems.

Most participants in the current study expressed that to be healthy was associated with certain abilities. If one is healthy, one has choices and is able to make them. Being healthy for a number of participants was tied to the issue of self-determination.

Castellano (2004) defined self-determination broadly as “the right of peoples to construct knowledge in accordance with self-determined definitions of what is real and what is valuable” (p. 102). An application of Castellano’s definition of self-determination to health might imply that one possesses the ability and the necessary resources to make free and informed choices about what one values as relevant pathways to health and is able to pursue them. Waldram (2006) argued that in spite of Canada’s efforts to colonize Aboriginal peoples, they have always maintained some degree of self-determination around health as evidenced by their ability to preserve their traditional ways of healing in the face of Western medicalization of health care. It may be said then that in their efforts to bring about self-determination within their culture, Aboriginal peoples seek to regain *control* of aspects of their lives; control that was taken from them in the process of colonization.

For participants in the current study, being healthy involved the ability to take care of oneself and to be able to get the care one needed. Inherent in this view was the notion of self-sufficiency. It is important to note that goals of self-sufficiency and self-determination were not end-goals of the individual, but rather, life prerequisites that

allowed one to be able to care for others. In the current study, participants linked being healthy to being able to care for others whether in the role of parent, or simply as the helping obligation of one community member to another. The Indigenous person's priority need for self-sufficiency as a criterion for fulfilling caring roles for others was similarly identified in the study by Salvalaggio et al. (2003). In their study, First Nations patients who were receiving kidney dialysis treatments far from their home reserves experienced significant stress when they lost their independence and sense of self-sufficiency. These notions were compounded when they perceived themselves to be a burden on others, while not being able to resume the social roles they had previously fulfilled in their community. In the same study, a lack of self-determination was experienced by participants when they did not experience autonomy over decisions being made about their treatment regimen.

Kirmayer, Sehdev, Whitley, Dandeneau and Issac (2009) provide further discussion of the Aboriginal need for self-sufficiency in their discussion of the term resiliency. While being self-sufficient may imply the ability to maintain oneself independently, resiliency as presented by these authors takes on greater relevance within Indigenous cultures in that resiliency is context dependent. That is, "Aboriginal resiliency must be understood in relation to the specific forms of adversity that Aboriginal individuals have faced" (p. 79) such as colonization, oppression and forced assimilation. Kirmayer et al. noted being resilient requires "holistic, complex, interacting relationships" (2009, p. 78) which link the individual's sense of well-being inextricably to that of the whole community.

One of the factors that impacted upon the self-sufficiency of participants in the current study was the issue of transportation. Living in this rural community presented many challenges for both young and older participants in terms of being able to afford reliable transportation or to be able to afford to provide financial compensation for others that might be able to provide them with transportation to the health centre or other health service within or outside the community. A lack of transportation was identified as a significant barrier to accessing appropriate health care for Native American caregivers of children with special needs in a study by Malach and Segel (1990).

While being fit and taking prescribed medicines were mentioned by some participants as part of the theme of being well, the action that was viewed by the majority of participants as central to being healthy was the notion of eating right. Many participants expressed concern over the changes that they had observed in the community over several decades, in terms of foods consumed and the methods used to prepare them. Many older participants recalled a time when community members were more likely to eat wild foods (e.g.: game, fish and deer) as a significant proportion of the diet. Many participants voiced concern about the high consumption of high-fat foods and foods high in starch and sugar especially by younger members of the community. A number of participants of all ages stated that there was a high rate of obesity among community members and this was particularly alarming among children and teens. Almost all of the participants stated that they had either been diagnosed with diabetes, or perceived themselves to be at high risk due to its prevalence within their own families.

While healthy food preparation and consumption were viewed as a priority concern in the overall health of the individual and community among participants within the current study, little was documented concerning the role of nutrition in the client experience within the 14 original articles focused upon in my literature review. However, a small number of other studies (Bruyère & Garro, 2000; Poudrier & Kennedy, 2008; Issak & Marchessault, 2008) that have been conducted with First Nations and Native American groups on the meaning of health brought forth similar participant concerns about the nutritional intake of their communities and the role that healthy eating plays in the maintenance of health. In a study conducted by Poudrier and Kennedy (2008) First Nations women were asked what they determined to be the meaning of a healthy body. One of the four themes that they identified was the importance of healthy eating and the purchase and healthy preparation of foods.

In the Poudrier and Kennedy (2008) study, most participants viewed a healthy diet as a combination of traditional and contemporary diets and the consumption of a balance of food choices was important in maintaining health. The findings of the Poudrier and Kennedy (2008) study were very consistent with the sentiments concerning healthy eating that were expressed by the participants in the current study. A study of diabetes in the Opaskwayak Cree Nation in Manitoba revealed that among participants, the steady decrease in the community's consumption of wild foods was viewed as a contributing factor to the increase in diabetes there (Bruyère & Garro, 2000). Similarly, participants within the study by Isaak and Marchessault (2008) viewed the increased consumption of "processed, convenience and fast foods" (p. 118) as a direct cause of ill

health in their community. In comparing the findings of studies that addressed healthy eating among participants with the findings of the current study, it seems apparent that while many Aboriginal peoples are aware of the importance of preparing foods in healthy ways and eating foods that were nutritionally balanced, many expressed a lack of knowledge of how to go about it. This was central to the comments of participants such as Candy, Hucks, Daisy, Fern and Hummingbird in the current study. It was a particular concern of younger participants who had children.

The subtheme of eating right as a central component of being healthy primarily addressed participant concerns around accessing healthy foods, knowing how to prepare them in nutritious and appealing ways, and raising community awareness concerning the importance of eating in healthy ways to lessen the diagnosis and impact of diabetes and obesity across the lifespan. However, given the relationship between healthy eating and fitness, I was surprised that there was only minimal discussion by some participants concerning fitness in association with the concepts of health and being healthy. Some reference was made by older participants concerning the way things used to be when there were few automobiles within the community and walking was the main form of transportation. Hucks and George recalled the need to have fitness and survival skills in the past in order to hunt for food and chop wood. Similarly both participants expressed concern about the inactivity of the young community members, but their inclusion of such comments was more in relation to their acknowledgement of high obesity rates in the community.

In response to the fourth question in the current study which asked community members what might have to change at the health centre to make it more meaningful to them, both Hummingbird and Daisy expressed the need for fitness programming and equipment that could be used by the community. They both stated that programs they had accessed at the health centre (such a yoga and tai'chi) were for “older” people and presented minimal challenges for younger community members who had the capability and desire for a more intensive physical workout. Colt stated that there used to an active hockey tournament system situated within the community’s ice arena, but that overtime, youth participation in hockey had declined.

The community houses an ice arena and a recently constructed skateboard park. The health centre does provide walking and other exercise programs. However, Daisy indicated that there is no location within the community to access fitness equipment or swimming facilities. While the notion of being fit was not commonly expressed by participants as a central component of health or being healthy, a number of participants did express the desire for changes in the health centre’s programming to provide fitness activities. Daisy, Hummingbird indicated that they would be more likely to use the health centre if more fitness activities and equipment were offered there or sponsored locally by health centre funding. Others such as Candy and Fern appreciated the transportation services that were provided by the health centre to swimming facilities outside of the community.

None of the 14 research studies used in my literature review addressed the issue of fitness as part of the client experience of health services. Although, this may not be

surprising in that the focus of these studies addressed the client experience of health services and more specifically, client experiences that resulted from interactions with health care providers. However, my examination of the broader literature for studies that examined that meaning of health among Indigenous peoples, revealed that physical activity figured more prominently in expressed meanings of being healthy than was evident in the current study.

Graham and Stamler (2010) studied perceptions of health held by the Plains Cree of the Thunderchild First Nation in Canada. Nine of the fourteen participants identified nutrition as an essential component of health while another prominent theme addressed the need to exercise regularly in order to obtain optimal health. The participants in the study by Poudrier and Kennedy noted the importance of safe walking trails to assist them in the engagement in regular exercise. Issak and Marchessault (2008) identified that participants spoke of a direct relationship between healthy eating and physical activity and the concept of health. Participants in this study cited advances in technology as a possible cause for the decline in community members' engagement in physical activity.

I am aware that most symbolic representations of the medicine wheel that are used by First Nations in Canada include a quadrant that addresses the importance of physical health as central component of a wholistic view of health. Given that physical health plays such an important role in the First Nations worldview of health, I am not surprised by the participant valuing within the current study of healthy eating as central to being healthy, but I do question why physical activity was not a common topic of participants' expressed view of health. It leaves me to wonder if the minimal existence of

a formal fitness infrastructure within the community (such as an exercise equipment, walking trails, more team sports, and swimming facilities) impacts upon participants' perceptions of health. Perhaps participants feel that they have greater power and control to change the way they eat as compared to the choices presented for pursuing greater physical fitness within their community. Such questions are worthy of exploration within the community of focus in light of the importance of physical fitness in the prevention and treatment of diabetes and obesity; both of which are prominently experienced and of considerable concern to community members.

I use the health centre. This overriding theme addressed the client experience of the health centre as a place one can go to access health care services within the community. The subthemes associated with this overriding theme addressed the primary reasons that participants visit or telephone the health centre: a) For information on health, b) For illness-related services, and c) to visit the traditional healer. Among those participants who reported recent use of the health centre most stated that they used a combination of health centre services that addressed their experiences of both health and illness.

The first subtheme addressed participants' client view of the health centre as a place to access information on health and illness information topics. Approximately one half of the participants had used the health centre recently and in most cases, the purpose of their visit or telephone call was to acquire information about health promotion/maintenance or a particular illness. A commonly expressed view of many participants was that the information provided was not of adequate depth to meet their

information needs. This was particularly true of diabetes education materials. It was felt that given the high rate of diabetes and other diseases within the community, the information contained in many pamphlets available on diabetes was already known by participants seeking greater knowledge in these areas. The expressed need for a greater depth of information on such issues as diabetes, parenting challenges, nutrition, fitness, attention deficit hyperactivity disorder and cancers was noted most among younger participants, many of whom were avid users of the Internet.

The current study revealed that a number of participants attended health centre information sessions (e.g.: guest speaker events, cooking classes, yoga and tai'chi classes). While many of the older participants who attended such classes expressed much satisfaction with the depth and scope of information provided, younger participants felt that there should be “levels” of classes in relation to fitness, nutrition and diabetes to suit different learning needs and capabilities. For many participants the availability of in-depth health information of greater depth than what is currently provided at the health centre (whether for health promotion or illness recovery) was an essential foundation upon which they could make informed decisions about health.

Within the health care literature, similar perspectives were noted regarding participants' perceived lack of adequate information to make informed health care choices. In the studies by Barr and Wanat (2005) and Kurtz et al. (2008), participants were offended by health care providers who offered health information and advice not asked for on obesity, diet, alcohol and drug abuse; information that was most often irrelevant to clients' informational needs, and life context and practices. A number of

studies noted participant experiences of health care providers who did not provide adequate explanations of diagnoses and treatments offered (Browne, 1995; Poudrier & Thomas Mac-Lean, 2009; Salvalaggio et al., 2003)

The second subtheme addressed the meaning clients assigned to the health centre in relation to services offered there for illness-related issues. In terms of medical diagnoses, diabetes was mentioned most often as an issue of concern that brought them to the health centre for blood glucose monitoring, foot care and related monitoring. Among those who used such health centre services, many found the health centre's regular staff to be knowledgeable and helpful. However, a number of participants noted that some non-Aboriginal health care providers who visited at the health centre from outside of the community, often lacked cultural understanding of the life contexts within which First Nations community members coped with diabetes. This finding was consistent with similar findings within the studies by Barr and Wanat (2005), Browne (2007), Browne et al. (2000), Bucharski et al. (2006), Garwick et al. (2002) and Poudrier and Thomas Mac-Lean (2009). It is important to note that the health centre does provide substance abuse and addictions counselling funded under the National Native Alcohol and Drug Abuse Program (NNADAP). While a few participants indicated an awareness that such services were offered at the health centre, no one shared their perceptions or experiences of this service area.

The third subtheme related to participants' use of the health centre as a trusted location for accessing a visiting traditional healer. For many such participants, the traditional healer was used in conjunction with Western medical services. This trend in

First Nations health service utilization was also noted by Warry (2007). It may be said that the health centre's provision of both traditional medicine and mainstream health services within the same location is a form of cultural integration of health services (Walker et al., 2010). Warry (2007) noted that "Most healers would suggest that Indigenous and biomedical therapies be pursued sequentially" (p 27). Warry stated that the integration of traditional healers and traditional medicine into health services is a strategy which promotes the reclaiming and revitalization of "Indigenous forms of knowledge that are central to the rejection of colonialism and the affirmation of Aboriginal culture" (2007, p. 27).

While participants in the current study appreciated the option to access the services of a visiting traditional healer at the health centre, it was noted by many that it was often a challenging experience to secure an appointment due to the high demand for his services. Recommendations of participants included the use of more than one traditional healer and the ability for community members to self-book some of the available appointment times on-line via a password-protected health centre website. Within the articles used for my literature search in Chapter 2, a small number of studies confirmed participant use of traditional healers in conjunction with their utilization of mainstream health services (Burcharski et al., 2006; Poudrier & Thomas Mac-Lean, 2009). Within the larger body of research, the resurgence in the use of traditional medicines and healers by First Nations communities is well documented (Castellano, 2004; Martin-Hill, 2009; Ten Fingers, 2005; Waldram, et al., 2006).

I don't use the health centre. This overriding theme addressed the meaning of the health centre as a place that participants knew little about, avoided due to a past negative experience there or simply did not use as their health care needs were met through family, Elders, and self-healing practices, or through health care services offered outside of the community. The subthemes associated with this overriding theme included: a) The health centre doesn't come to mind when I am sick or well, b) I don't know what they do/offer there, c) I'm not comfortable there; it feels strange and unfamiliar, d) I go to family, friends and Elders, and e) I try to heal myself. The two subthemes that reflect findings of previous studies included subtheme, "I am not comfortable there; it feels strange and unfamiliar" and "I try to heal myself". These subthemes address findings that have been previously documented in the Indigenous health care literature in relation to client's experiences with health care services in a variety of settings (largely with a Western health care delivery framework).

The subtheme "I am not comfortable there; it feels strange and unfamiliar" is similar to the findings of a number of studies from the 14 studies included in my literature review at least in terms of the client experience. Baker et al. (2000) noted that participants often felt strange in health care settings, in part because they felt unfamiliar with health care routines and did not know what to expect, Browne et al. (2000) noted that lack of familiarity of health service personnel left some participants feeling vulnerable, isolated and marginalized. Dodgson and Struthers (2005) stated that many participants in their study felt marginalized as a result of their lack of familiarity with the complexity of Western, biomedical health care systems and from their observation of

abruptness and professional distancing by health care professionals. Dodgson and Struthers (2005) noted that participants' experiences of feeling strange in an unfamiliar place were further exacerbated by their own experiences of colonization from the legacy of the residential school system and discriminatory treatment by health care providers. Bucharski et al. (2006) concurred with the findings of Dodgson and Struthers (2005) that participants recalled feeling overwhelmed in an unfamiliar and complex health care system and this resulted in their reluctance to share personal information with health care providers. Salvalaggio et al. (2003) stated that participants' experiences of loneliness were compounded by unfamiliar medically prescribe protocol.

Most participants seemed unaware of the health centre's primary service mandate in relation to health promotion and illness and injury prevention and wondered why there was no physician full time at the health centre to provide diagnosis and treatment of illnesses. 'We need doctors there' was a common theme expressed by both those who frequented the health centre or reported using no services there. Others felt that the community had a "right" to locally accessible physician and nurse practitioner services at the health centre location and this was particularly expressed by those who had travelled to other First Nations reserves in Canada (many of which supported smaller populations than the community of focus) and maintained the services of at least one (and often many) physicians on a regular basis within their community's 'health centre complex'.

For some participants such as Red Sky and Colt and White Wolf, there was an expressed level of frustration that the community did not make better use of the location given the costs of staffing and service provision there. Some assumed that the health

centre services were not well used by the community and put forth several ideas as to why they believed this was so.

Common reasons stated for the lack of actual use by individual participants or assumed avoidance of the health centre by others related to being indifferent in regard to the health center simply because they were unaware of the services provided there and were reluctant to go there to find out. Red Sky and Colt stated “it is not our way” to go and ask people directly what they do and what they offer. Such information is often received by word-of-mouth within the community. Other participants stated that their lack of use of the health centre either stemmed from a negative past experience there or simply because they rarely became ill. Most participants used a combination of traditional and contemporary/Western health services. Some engaged in self-healing for day-to-day coughs and colds using traditional remedies and over-the-counter Western pharmaceutical preparations and only “thought of” seeking Western-oriented health care services outside of their community when they could not control the symptoms of their illnesses through self-healing. A key finding of the present study that was expressed by a number of non-users of the health centre, was that if they knew what services were offered, who provided them and when, they would be more inclined to “check the health centre out”. This finding lays the foundation for discussion among community members regarding other ways (such as information technology in the form of health centre website) that could be used to disseminate up-to-date information on health centre programs.

I have provided discussion concerning how the findings of the current study confirmed a number of findings from the literature concerning the meaning that First Nations peoples have assigned to the client experience of health services that are associated with both Indigenous and Western oriented health care services. There are also a number of areas in which the current study has contributed substantive new areas of knowledge concerning the First Nations client experience of health services within their own community.

The current study sheds important light on the meaning that one First Nations community assigned to their experiences at a health centre and suggests reasons why First Nations clients may elect to use or avoid accessing health services provided by health centres within their own communities. Some clients viewed their health centre services as more likely to be culturally congruent in that it was administered and housed locally and employed health care providers who were more likely to understand and respect First Nations community members. Among the 12 participants approximately half stated that they regularly used the health centre and valued it primarily for its provision of health information and health maintenance services (especially in relation to diabetes and pre- and post-natal services).

However, the reasons expressed for avoidance of the health centre and its programs provide new insights into community members' decisions regarding health service utilization. Within the community of focus, study participants stated that a common reason for not accessing health centre services was their general lack of knowledge of services offered and a reluctance to ask. This finding has implications in

relation to how health centres within First Nations communities successfully promote their services, especially in light of advances in communication technologies (such as the increasing use of the Internet) and other electronic forms of technology (e.g. social media).

The study revealed that some community members avoided the health centre because they viewed the health centre as a health care facility which needed to provide greater integration of services beyond its central mandate of health promotion and illness- and injury prevention. This finding leads to implications concerning the importance of self-determination for the researched community in making decisions concerning how health care dollars are allocated within the community. It also confirms the sentiment expressed in the literature that greater collaboration and consultation needs to take place between the government and local First Nations communities within the health transfer process to increase community valuing of services that are provided locally.

The current study sheds light on the community's vision of a health centre as one that should address the needs of the community in relation to both health and chronic illness. That is, it is important for many community members to be able to access services across a broad health continuum at their health centre, or they are likely to go elsewhere for services or put off or avoid accessing health services altogether.

The Federal Government continues to share responsibility for the provision of health services to First Nations peoples living in their home communities. The current study fills a gap in the literature in term of understanding some of the reasons why community members may or may not use local health care services even when they are

perceived as culturally congruent and are provided within close proximity to their homes. However, future studies are needed within other First Nations communities in Canada to examine what contextual factors influence client decisions concerning access to health care services and what similarities and differences exist among First Nations communities.

Implications

The current study of the expressed meaning of the client experience at a health centre within a Southern Ontario First Nations community has given rise to a number of implications. I present here recommendations for consideration concerning the nursing practice, education, research and policy. I conclude this section with a brief set of considerations for the First Nations community of focus concerning participants' expressed suggestions for what they envisioned as the ideal health centre in their community.

Nursing education. This study demonstrated that in order for nurses (and other health professionals) to provide culturally safe and competent care to First Nations peoples, they would benefit from an increased understanding of the broader life contexts within which First Nations experience health and illness. The use of cultural safety as a nursing approach can assist nurses in addressing the power differentials that exist within nurse-client relationships. A recent, comprehensive document titled *Cultural Competence and Cultural Safety in Nursing Education: A Framework for First Nations, Inuit and Métis* (Aboriginal Nurses Association of Canada, Canadian Association of Schools of Nursing, & Canadian Nurses Association, 2009) was established to “assist educators to

foster cultural competence and cultural safety” among students of nursing education programs in Canada (p. 3). This document provides educators with six core nursing education competencies that will prepare nursing graduates to provide culturally appropriate care for Aboriginal peoples. These competency areas include 1) postcolonial understanding; 2) communication; 3) inclusivity; 4) respect; 5) Indigenous knowledge; and 6) mentoring.

1. I recommend that all programs at the college and university level that prepare students for careers in nursing include address to the six competencies presented above within their program curricula.
2. Internal and external nursing curricular evaluation strategies need to be established to “ensure that curricula, programs, faculty members, students, and resources collectively align and foster educational excellence in the area of Aboriginal nursing” (p. 5).
3. I recommend that the curricula of in-service education and training programs within the health care system continue to provide nurses with regular opportunities to develop knowledge and skills in relation to the provision of care for First Nations peoples as marginalized and vulnerable populations. The education content of such programs can build upon the competencies addressed within nursing education curricula consistent with the six core competency areas listed above.
4. Nursing education programs need to provide greater opportunities for students to engage in direct interface and dialogue with persons of First Nations

heritage. This may take place through the inclusion of First Nations peoples as lecturers and guest speakers in the classroom setting, and through the hiring of First Nations individuals to serve as standardized patients in health care simulation training exercises that involve students. Appropriate curricular funding needs to be set aside to ensure that those of First Nations heritage will be appropriately compensated for their sharing of time and expertise.

Nursing practice. It is important for nurses not to underestimate the significant role that they may play in the promotion of health and the prevention of illness for First Nations peoples in Canada. They occupy a central and influential role within the larger health care system and thus have an ethical obligation to advocate for the reduction of health inequities that perpetuate poor health outcomes for First Nations populations. However, nurses also occupy a position of power within the nurse-client relationship leading to its potential to be both nurturing and oppressive.

1. As a concept, knowledge translation no longer belongs exclusively to the domains of academics and researchers. It is important for nurses within First Nations health centres to understand the importance of providing health care knowledge to First Nations peoples in ways that are understandable, useful and appropriately addresses each community's unique knowledge needs and preferences. Nurses and other health care providers within First Nations health centres can play an important role in evaluating health education materials to ensure that they address the unique needs of community members.

2. It is essential for nurses to constantly engage in reflexive activities that will assist them in evaluating their own cultural biases and whenever possible, to seek opportunities to gain knowledge and respect for Indigenous worldviews of health and health practices that differ from their own. This includes engagement in thoughtful examination of the negative discourses that address Aboriginal peoples within the health care system and the degree to which nursing practice routines may perpetuate actions such as stereotyping, discrimination and racism toward Aboriginal populations.
3. First Nations communities in Canada have each formed within unique historical, cultural, economic, social, political, geographical and linguistic contexts. It is important for nurses to recognize the uniqueness of each First Nations client and to take the time to listen respectfully and inquire about clients' cultural beliefs and practices (Garwick et al., 2002) within the nursing assessment. Such cultural practices and beliefs need to be incorporated into the nursing plan of care.

Nursing research.

1. As a follow-up to this study, I recommend that research be conducted within the community of focus to gain an understanding of community members' client experiences of health care services resulting from the recent addition of physicians and nurse practitioners to their community setting. What impact does the presence of nurse practitioners, and physicians within the community

have upon the community's utilization of services provided by the health centre?

2. Although the findings of this study cannot be generalized to other First Nations groups it may be possible to use the findings of this study to pose new questions concerning the ways in which other First Nations experience the role of client within programs provided by their communities. For example, what is the variability in the types of services that First Nations groups receive in relation to health promotion and illness prevention services within their own communities? What contextual factors determine the likelihood that a community will have local access to nurse practitioner and physician services within the health centre structure? What is the relationship between geographic location (urban versus rural and remote locations) and the presence of a stand-alone health centre within a First Nation community?
3. Research needs to be conducted to evaluate the degree to which current government-funded, First Nations print and electronic materials on health promotion and education appropriately address the learning needs and preferences of First Nations community members across the lifespan in terms of scope and depth of content. This is particularly significant at a time when the generation of First Nations community health care service mandates and the print materials that accompany them are still largely generated and distributed from the First Nations and Inuit Branch of Health Canada as a central (top-down) government bureaucracy. In particular, increased

consultation and collaboration with First Nations communities needs to take place in order to determine their current needs and preferences for up-to-date information on both health and illnesses. The findings of the current study indicated that participants wanted access to culturally appropriate health education materials that contained a much greater depth of information than that which is available at their health centre. It would be important to know if other First Nations communities express similar informational needs as this would indicate the need for a comprehensive evaluation of the design and content of current materials that are distributed by the First Nations and Inuit Branch of Health Canada and other Aboriginal health organizations to First Nations communities.

4. The use of participatory processes is highly relevant for use with First Nations communities. Its use promoted transparency in the research process and facilitated shared decision making at every phase of this research process. For example, the involvement of both health centre and research centre staff in the piloting of the research questions for cultural relevancy was essential to ensure the success of the interview process. The active involvement of the community advisory committee in the participant recruitment phase of the study was the primary factor that resulted in a participant sample that was diverse in its characteristics and well representative of the community's population.

5. In doing research with First Nations peoples, I learned the value of hiring community members to assist me in the conduct of my research. However, as a doctoral student, it was important for me to be involved as much as possible in the “doing” of the research, which in turn limited the extent to which local First Nations experts could contribute to the research process such as through interviewing participants. My recommendation to nurses who plan to partner with First Nations populations in the conduct of research, is to recognize that front-line workers possess considerable life experience which “represents a wealth of knowledge concerning community life” (Warry, 1990, p. 65). Therefore, they, along with Elders and other community members need to be actively invited to engage in the conduct of the research project and be suitably compensated for their time and expertise.
6. The conduct of respectful research in partnership with First Nations communities “takes more time, more money and, arguably moral fibre” (Schnarch, 2004, p. 84). It is important that nursing graduate students who plan to engage in research with First Nations communities using participatory processes recognize the considerable investments in time, costs and up-front learning that are required to successfully (and respectfully) partner with First Nations communities, and to provide them with the necessary time needed for trust building.
7. The application of Ermine’s (2000) concept of ethical space was of significant importance in helping me as the researcher to both engage in the research

partnership with the community and perhaps more important, to examine my own stance as a researcher within this cross-cultural research partnership. I would recommend that nurses engaging in cross-cultural research with Indigenous communities take time to understand and conceptualize the relationships between Indigenous and Western knowledge systems through engagement in reading the works of Indigenous scholars such as Professor Ermine.

8. The van Manen (1997b) method of data analysis was culturally congruent for use within the current study with First Nations peoples in that his hermeneutic approach to data analysis led to my engagement in a circular relationship with the data and with participants in our joint interpretation of the data. I recommend that more phenomenological research be conducted with First Nations populations using van Manen's data analysis method to determine its cultural relevancy and applicability with First Nations research in Canada.

Nursing policy. A definition of policy that was offered by Warry (1990) stated that "Policy may be broadly defined as a set of values for planned action which must take place within an environment of limited or restricted financial resources" (p. 64). This definition is timeless if one considers the current funding inequities associated with the care of Aboriginal peoples in Canada. Discussion within Chapter 2 of this dissertation addressed the challenges and successes to date in relation to the health transfer process under which First Nations are gradually assuming greater control of health services within their communities. Nurses working within or in close proximity to First Nations

communities and/or with First Nations clients are encouraged develop an understanding of the health transfer process and the unique health issues faced by First Nations peoples in Canada. It is important for nurses and nursing organizations to advocate for greater Federal Government collaboration and consultation with First Nations to promote community-centred care that addresses the unique health care needs and preferences of each First Nations community.

Nursing advocacy of this nature can be accomplished by joining and supporting the Aboriginal Nurses Association of Canada as a regular member (for nurses of Aboriginal heritage) or associate member (for non-Aboriginal nurses). Similarly, nurses can use their national, provincial and territorial professional nursing organizations (such as the Canadian Nurses Association and the Registered Nurses Association of Ontario) to bring the health issues faced by First Nations peoples to greater national awareness and to advocate for more culturally safe and appropriate care for First Nations populations.

First Nations Community Health Centre. Table 4 - Table Summary of the Participants' Collective Vision of an Ideal Health Centre provided a detailed compilation of participants expressed ideas concerning their vision of an ideal health centre within their community, and how they might make changes within their health centre if they had the power to do so. As a non-First Nations researcher within this study, I am comfortable in providing implications in relation to what I have learned concerning the findings of this study for nursing research, education, practice and policy. However, I do not feel that it is my place as an outsider to the community to draw implications from the participants' expressed vision of an ideal community health centre, and to do so would be

colonizing and disrespectful of the community's right to self-determination. Implications that may be drawn from the participants' collective vision of an ideal health centre are left to members of the researched community to generate and dialogue based upon the findings of this study. I documented the participants' common vision for their use in relation to First Nations knowledge generation and translation.

Limitations

This research study was limited to the study of the meaning of the client experience at a health centre within one First Nations reserve. Contextual factors unique to each First Nations community have a direct impact upon the type of health services available to its members. Some of these factors include population size, land mass, proximity to urban centres, and the method chosen by the community to assume control of its health services under the Federal Government's Health Transfer Process. In addition, historical, economic, political, social, cultural and related factors all play significant roles in the development and delivery of health services to each First Nations community. Therefore, the transferability of the findings of this study are limited.

While the participant sample used for this study was significantly diverse in its demographic characteristics, the sample size of 12 participants provided only minimal representation within each of the young adult, middle aged and older populations. It is important to understand how each age group views and utilizes the services of the health centre. Therefore, further studies might be considered within the community to focus on client perspectives by age cohort. Such findings may help the health centre in its efforts

to promote health and package information in ways that would be most useful to each age group.

The data collection period of my research study was completed at a time prior to the recent addition of the services of nurse practitioners, a physician and a pharmacy to the community. Therefore, further study within the community might be considered to gain an understanding of how the client experience of the health centre has changed with the very recent availability of services provided by these health care personnel. I would recommend that more studies be conducted to gain an understanding of the unique client perspectives and experiences of health promotion and illness prevention services within other First Nations communities across Canada, so that more in-depth knowledge can be formed concerning ways in which First Nations peoples perceive, experience and utilize health promotion and illness and injury prevention services.

Conclusion

This research study was the first of its kind to gain an understanding of the meaning of the client experience in relation to a First Nations health centre in Southern Ontario. The conduct of this study using participatory processes provided an opportunity for participants to give voice to their experiences in relation to the provision of health promotion and illness and injury prevention services within their own community. While the stories and perspectives of each participant were unique and grounded within their own life experiences, the collective voice yielded three distinct themes for understanding their meaning of the health centre client experience. Their views on health and being healthy revealed the importance of self-determination and self-sufficiency in relation to

their health. Being healthy meant being able to take care of oneself and others. While a common sub-theme addressed health as a balance of mind, body and spirit, for the majority of participants, the preparation and consumption of healthy foods was viewed as one of the most significant ways to promote and maintain the health of the individual, family and the community as a whole. The client's priority needs for self-sufficiency, self-determination in decision making about health decisions, and their valuing of nutrition as a road to health all have implications for health care provision from an health promotion and illness prevention standpoint.

The second and third themes resulting from the study provided insight into the ways in which the First Nations community of focus views the health centre positively, negatively or from a place of indifference. For those who actively used the health centre, much appreciation was expressed for the dedication of the staff and the variety of information and services that were available there in relation to health promotion. Others valued the numerous screening services in relation to diabetes and other diseases, and the information sessions that were provided on a variety of topics. Others used the services of traditional healers at the health centre and placed a high value on the revitalization of traditional healing practices in combination with Western health care approaches.

Those who reported not using the services of the health centre identified several reasons that included a lack of knowledge of services offered, not feeling comfortable or familiar with the health centre personnel or its structure (space) and their choice to address their health needs through other avenues such as family, friends, Elders and self-healing, or via health care services outside of the community. It is important to note that

many of the younger participants who did not use the health centre stated that it was largely due to the fact that they were unaware of the services provided there and would go there if they became aware of a service offering that was perceived as valuable to them. This finding has implications for the ways in which health centres within First Nation communities promote their services to different age groups. The younger population preferred overall to access information about health centre staff and services independently, through the Internet.

Limitations and multiple implications of the study were provided in terms of nursing research, education, practice and policy. Other suggestions for modifications of the existing health centre within the community of focus can be drawn from the study findings that yielded a collective vision of the participants concerning what they viewed to be the ideal health centre within their community.

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Appendix A – Glossary

Glossary

Colonialism

While it has been defined many ways in the literature, with respect to Indigenous peoples in Canada, colonialism may be viewed as:

A theoretical framework for understanding the complexities of the relationship that evolved between Indigenous peoples and Europeans as they came into contact and later sustained those initial relationships in building a new reality for both peoples in North America. Specifically, colonialism is the development of institutions and policies by European imperial and EuroAmerican settler governments towards Indigenous peoples. (Alfred, 2009, p. 45)

One policy of colonialism in Canada in the 19th and 20th centuries was the forced attendance of Aboriginal children at over 130 residential schools across the country that were designed to assimilate them into the non-Indigenous Canadian society. The legacy of the residential school system accounts for many of negative life conditions faced by Aboriginal populations today (Aboriginal Healing Foundation, 2002). In relation to First Nations, colonialism was described by Gagné (1998) as “a seed of trauma as it leads to dependency, then to cultural genocide, racism and alcoholism. These in turn lead to sexual abuse, family violence, child abuse, and accidental deaths and suicide” (p. 358).

Colonization

A process that involved “invasion and eventual domination of North America by European empires” (Alfred, 2009, p. 45).

Community

While there are many definitions of this term in the literature, I chose to use the following one as it relates well to the notion of community from an Indigenous worldview. A community is:

A system of relationships within Indigenous societies in which the nature of person-hood is identified. This system of relationships not only includes family, but also extends to comprise the relationships of human, ecological and spiritual origin. Community is a structure of support mechanisms that include the personal responsibility for the collective and reciprocally, the collective concern for individual existence. (Ermine, et al., 2004, p. 5)

Community Advisory Committee

An ad hoc committee was established by the researched community with whom I could engage in ongoing dialogue, collaboration and guidance regarding the research process of my doctoral study. Its composition was made up of a representative of the community's health committee, one representative from the community's research committee, and one member who represented the community at large.

Cultural Advisor

Persons to whom I was referred by the researched community in order to seek guidance on issues related to Ojibwe (*Anishinaabemowin*) language translation and cultural protocols associated with the researched community.

Community Health Representative

In Canada, the term Community Health Representative (CHR) is used to describe a paraprofessional health provider role within First Nations and Inuit communities that was established in 1962 by Health and Welfare Canada under the Community Health Representatives Program. The role was created to enhance health service provision within rural and remote Indigenous communities. By 2004, 900 CHRs were practicing in 577 First Nations and Inuit communities in Canada. CHRs carry out a range of health services based upon the needs of their communities including health promotion and illness prevention, screening and immunization, some emergency treatments, home visits, mental health and addictions counselling, pre/postnatal care and care of the elderly (National Indian & Inuit Community Health Representatives Organization, 2004).

Elder

Marlene Brant Castellano, a noted Mohawk scholar in Canada described Elders within First Nations communities as “the persons who are most knowledgeable about physical and spiritual reality, the teaching and practice of ceremonies, and the nuances of meaning in Aboriginal languages” (p. 101).

Health Transfer Process – Three Approaches

In 1989, under a new Health Transfer Policy, the First Nations and Inuit Health Branch of Health Canada began transferring responsibility for, and control of selected health programs and services to First Nations communities situated below the 60th parallel. Three approach options for the transfer of control of health services existed, namely “*Health Services Transfer, Integrated Community-Based Health Services, and Self-Government*” (Health Canada, 2004, p. 1). Not

all communities began the transfer of control immediately. The rate at which each community took on the responsibility for, and control of health services within their community depended upon their “interests, needs and management capacity” (p. 1).

Health Services Transfer. Involves a process that gradually moves control of resources and responsibility for community health services and programs into the hands of First Nations and Inuit communities. The process includes the transfer of knowledge, capacity and funds so that communities can manage and administer their health resources based on their own community needs and priorities. (p. 5)

Integrated Community-Based Health Services Approach. This approach to First Nations and Inuit control of health services and related resources involves the community signing one Contribution Agreement for specific types of community health services which the community wishes to manage. The two key components of the Integrated approach are the establishment of the community health management structure and the creation of a global budget funding arrangement. The community health management structure can take the form of a health committee or board, or a health coordinator. The funding agreement can be approved for a period of three to five years, with the budget renewable annually. (p. 23).

Self-Government. In 1995, the federal government announced the Inherent Right to Self-Government Policy. This Policy supports First Nations Inuit control over all aspects of their lives. Self-Government thus introduces a third approach for First Nations and Inuit communities to increase their control over health programs and services. Under this Policy, First Nations may be entitled to make certain laws governing their community with respect to health. Furthermore, the range of resources for health programs which can be included in a Self-Government arrangement is greater than those included in a Health Services Transfer arrangement and may include fixed assets and services under the Non-Insured Health Benefits Program. The flexibility in terms of how resources are allocated is also greater and the reporting requirements are fewer. (p. 31)

Indian

Under the Indian Act of 1876, an Indian in Canada is defined as one who is “registered as an Indian or is entitled to be registered as an Indian” (p. 2). The term Indian is not inclusive of Inuit peoples under this act.

Indian Act

The 1867 Constitutional Act gave the Parliament of Canada legislative power over Indians and the reserve lands that they occupied. According to Hurley (1999),

The first consolidated *Indian Act* reflected the government's preoccupation with land management, First Nations membership and local government, and the ultimate goal of assimilation of Canada's Aboriginal population. *The Indian Act* remains the principal vehicle for the exercise of federal jurisdiction over "status Indians," and governs most aspects of their lives. It defines who is an Indian and regulates band membership and government, taxation, lands and resources, money management, wills and estates, and education. (para.1)

Over the years, several revisions have taken place to the *Indian Act* but essentially, the basic legislative tenets of the document remain intact (Royal Commission on Aboriginal Peoples, 1996).

Medicine Wheel

The medicine wheel may be represented by:

A circle divided into four quadrants, or segments, which are separate but interconnected. This state of separateness but interconnectedness is sometimes depicted visually with feathers placed between each quadrant and the four quadrants joining in the centre. The colours of the quadrants vary between nations. For instance, the Cree medicine wheel consists of blue, yellow, red, and white, whereas the Ojibway and Algonquin teachings substitute the blue with black. (Lavallée, 2009)

Reserve

Under the Indian Act of 1867, a reserve in Canada is defined as "a tract of land, the legal title to which is vested in Her Majesty, that has been set apart by Her Majesty for the use and benefit of a band" (p.3).

Surveillance

Surveillance is an epidemiological term used in the health care field.

[It] includes the ongoing collection of data, and the review, analysis and dissemination of findings on disease incidence and prevalence, hospitalizations and deaths. Surveillance can also collect information

concerning the knowledge, attitudes and behaviours of the public with respect to practices that prevent cancer, facilitate screening, extend survival and improve quality of life. (Probert & Poirier, 2003)

Traditional Knowledge

The following description of traditional knowledge has been drawn from the recently revised Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCP2):

Traditional knowledge – the knowledge held by First Nations, Inuit and Métis peoples, the Aboriginal peoples of Canada. Traditional knowledge is specific to place, usually transmitted orally, and rooted in the experience of multiple generations. It is determined by an Aboriginal community's land, environment, region, culture and language. Traditional knowledge is usually described by Aboriginal peoples as holistic, involving body, mind, feelings and spirit. Knowledge may be expressed in symbols, arts, ceremonial and everyday practices, narratives and, especially, in relationships. The word tradition is not necessarily synonymous with old. Traditional knowledge is held collectively by all members of a community, although some members may have particular responsibility for its transmission. It includes preserved knowledge created by, and received from, past generations and innovations and new knowledge transmitted to subsequent generations. In international or scholarly discourse, the terms traditional knowledge and Indigenous knowledge are sometimes used interchangeably. (p. 108)

Appendix B - Literature Review Key Terms and Search Strategy

Literature Review Key Terms and Search Strategy

| Key Search Terms | Databases | Internet Sites and Related Sources |
|---|--|--|
| description, encounter, experience, interaction, meaning, opinion, perception, perspective, story, voice | Bibliographic of Native North Americans | Aboriginal Health Research Network Secretariat |
| | CINAHL | Association of Ontario Health Centres |
| care recipient, client, patient, Indian, First Nations, Métis, Aboriginal, native, Indigenous | First Nations Periodical Index | Canadian Institutes of Health Research (Institute of Aboriginal Health Research) |
| | Health & Wellness Resource Centre | Indigenous Peoples Health Research Centre |
| community health centre/service, clinic, health care, health access centre, health promotion, prevention, treatment | Medline via OVID & Scholars Portal & PubMed | Local Health Integration Network |
| | Ovid Nursing | National Aboriginal Health Organization |
| health care professional/provider/worker/person, | ProQuest Nursing & Allied Health Source | National Collaborating Centre for Aboriginal Health |
| | PsychInfo | National Institute of Health Research |
| | PubMed Central Canada Scholars Portal (including E-Journals @ Scholars Portal) | Network Environments for Aboriginal Research BC |
| | | Public Health Agency of Canada |

Appendix C – Table Summary of the Critical Review of the Relevant Literature

Table Summary of the Critical Review of the Relevant Literature

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|--|--|--|--|
| <p>Baker, C. Daigle, M.C. 2000 Cross-cultural hospital care as experienced by Mi'kmaq clients. <i>Western Journal of Nursing Research</i>, 22(1), 8-28.</p> | <p>Qualitative - interpretive</p> <p>Purpose: To investigate how “Mi'kmaq from Big Cove reserve in New Brunswick describe their experiences with caregivers during a recent hospitalization” (p. 10).</p> <p><i>n</i> = 10 adult participants (8 females/2 males) of Mi'kmaq ancestry representing a broad range of demographics who had recently been hospitalized at three local hospitals.</p> <p>Data were collected via face-to-face interviews using open-ended questions</p> <p>The research team used the five steps of interpretive interactionism (Denzin, 1989) to guide data analysis.</p> | <p>Reported negative experiences included feeling and being misunderstood as a result of the differences between the Mi'kmaq and mainstream cultures, feeling “like a stranger” (p. 15) and feeling insecure in an unfamiliar place. Participants experienced feeling demeaned as a unique person. The feelings of insecurity and being misunderstood resulted from not knowing what to expect and from feeling reluctant to ask for information so as not to cause trouble.</p> <p>Positive hospitalization experiences resulted when health care providers demonstrated kindness through attentiveness, allowed family visits and treated the patient as an equal.</p> | <p>The rigor of the study was increased through the validation of findings with a small number of community council representatives and Elders. However, actual participants were not consulted to validate the findings. The researchers maintained an auditable decision trail.</p> <p>Greater use of quoted examples from participant narratives would have enhanced the reader's understanding of the identified interview themes.</p> |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|---|--|--|--|
| <p>Barr, D. A. Wanat, S. F.</p> <p>2005</p> <p>Listening to patients: Cultural and linguistic barriers to health care access</p> <p><i>Family Medicine</i>, 37(3), 199-204.</p> | <p>Qualitative - interpretive</p> <p>Purpose: "... to develop a better understanding of low-income, minority patients' perceptions of the culturally and linguistically related characteristics of their recent encounters with local health care organizations (HCOs)" (p. 200).</p> <p><i>n</i> = 41 low-income adults (gender composition unspecified) who used local community based clinics for their medical care.</p> <p>Data were collected using 11 open-ended questions and four ethnically homogenous focus groups formed by participants' ethnic affiliation with "African American, Latino, Native American, and Pacific Islander" groups (p. 199).</p> | <p>Consistent with all four focus groups were reports of patient stereotyping and discriminatory behaviour by physicians around obesity, diet and alcohol consumption. All four groups reported dissatisfaction with physician interactions as often appearing hurried and doctors not allowing adequate time to listen attentively to patients' comments. The Native American focus group reported overall greater satisfaction with the medical staff as compared with the non-medical staff and a preference for medical staff.</p> <p>The Native American group stated that they tended to ignore physician advice related to diet, obesity and alcohol as they perceived it to be offered to them based upon negative stereotyping by physicians and other health care staff.</p> | <p>Open-ended interview questions and thematic analysis were generally congruent with a qualitative research approach. Two members of the research team were used to code the data and they reported an inter-coder reliability of agreement greater than 95%</p> <p>Neither a philosophical foundation, nor specific methodological qualitative approach was identified for the thematic analysis. The specific size of each of the focus group was not stated.</p> |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|---|---|--|---|
| <p>Browne, A. J. 1995 The meaning of respect: A First Nations perspective. <i>Canadian Journal of Nursing Research</i>, 27(4), 95-109.</p> | <p>Qualitative- ethnography</p> <p>Purpose: To explore and “... to provide descriptions of respect as a phenomenon occurring during clinical interactions from the perspective of Cree-Ojibway key informants” (p. 98”).</p> <p><i>n</i> = 5 First Nations adults 4 females/1 male) aged 27-51</p> <p>Data were collected using in-depth interviews in a Cree-Ojibway community in northern Manitoba over a period of six weeks based on interview techniques outlined by Spradley (1979).</p> <p>Data were analysed by Schwartz-Barcott and Kim (1993) based upon an adaptation of the work of Schatzman and Strauss (1973).</p> | <p>Patients’ experiences of feeling respected or not respected in a clinical interaction can have a powerful impact upon patients’ valuing of, and comfort within health care interactions.</p> <p>Clinician behaviours that were perceived by participants as being respectful included (a) treating the client as an equal, (b) being accepting of others, (c) listening attentively to patients, (d) making genuine efforts to understand the patient’s point of view and life situation, (e) providing adequate information upon which patients can make decisions, and (f) demonstrating sincerity in one’s verbal and non-verbal behaviour.</p> <p>Non-respectful clinician behaviours included failure to provide adequate privacy, inadequate provision of health information, not acknowledging the patients’ unique situations and perspectives, and the demonstration of negative or discriminatory behaviours.</p> | <p>Rigor was maintained through validation of the thematic analysis with participants and through the use of a journal.</p> <p>The philosophical and methodological foundations of the study were clearly explained and the description of the method of data collection and analysis reflected these frameworks.</p> <p>The small sample size was limited to five participants with a limited age range not exceeding 52 years. Data obtained by older participants may have yielded further rich data on the topic of inquiry</p> |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|--|---|--|--|
| <p>Browne, A. J. 2007 Clinical encounters between nurses and First Nations women in a Western Canadian hospital. <i>Social Science & Medicine</i>, 64(10), 2165-2176.</p> | <p>Qualitative - ethnography Purpose: To “explore the sociopolitical context of nurses’ encounters with First Nations women in a Western Canada Hospital” (p. 2165) and to gain an understanding of how these interactions shape relations between nurses and First Nations women n = 35 composed of 14 First Nations female patients of a Western Canadian hospital, 17 hospital nursing staff and 4 additional Aboriginal health experts of First Nations heritage (non-hospital staff) who worked as registered nurses and community health representatives within First Nations communities. The researcher use of participant observation over nine months to observe nurse-patient interactions. The data were drawn from in-depth interviews.</p> | <p>The study suggested that both prevailing discourses and assumptions about Aboriginal peoples, women, and culture in Canada are embedded in the routine nature of clinical encounters between health care providers and Aboriginal clients. Such discourses and assumptions often perpetuate colonizing attitudes that affect the positioning of the client within the therapeutic relationship and negatively impact upon the overall quality of health care for Aboriginal peoples. Assumptions and a lack of knowledge of presumed cultural differences within the nurse-client relationship manifested as social distancing on the part of both nurses and Aboriginal patients. This resulted in a reduction in the quality of clinical interactions and in the overall health care experience. The study yielded substantive knowledge concerning how nurses’</p> | <p>A particular strength of the study was the author’s detailed address to the unique sociopolitical factors that influenced health and health service access for the specific First Nations community from which the sample was drawn. Given that 14 of the 35 participants were described as Aboriginal patients, a greater representation of discussion regarding their unique perspectives is warranted.</p> |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|--------|--------------------|---|---------------------------|
| | | beliefs about Aboriginal peoples influence the nature of the nurse-client relationship in the hospital setting. | |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|--|--|--|--|
| <p>Brown, A. J. (2000) Fiske, J-A. Thomas, G. First Nations women’s encounters with mainstream health care services and systems. <i>British Columbia Centre of Excellence for Women’s Health</i> website.* <u>and</u> Browne, A. J. (2001) Fiske, J. First Nations women’s encounters with mainstream health care services. <i>Western Journal of Nursing Research</i>, 23(2), 126-147.*</p> | <p>Qualitative - ethnography</p> <p>Critical and feminist ethnographic theoretical base</p> <p>Question: “How do First Nations women from a northern reserve community describe their encounters with local mainstream health services? How are these encounters shaped by social, political, and economic factors?” (p. 130)</p> <p><i>n</i> = 10 First Nations women from a north western reserve in Canada</p> <p>Data were collected during two face-to-face interviews and analysed using the techniques of van Manen (1997b)</p> | <p>First Nations women’s experiences with mainstream medical services were both “invalidating” (p. 133) and “affirming” (139). Negatively perceived encounters with health personnel included experiences of racism, dismissal of reported symptomology, negative stereotyping, vulnerability and professional disregard for personal circumstances. Positive or affirming encounters with health personnel were marked by perceptions of exceptional care, overt recognition and respect for personal and cultural identity, and the ability to interface with the same health care provider over a long period of time. Nurses and other health care providers tend to discount the social, historical, political and other factors which the First Nations client views as central to his/her health experience.</p> | <p>The use of critical and feminist ethnographic approaches were highly relevant to the research question given the First Nations history of oppression and colonization and the issue of power dynamics within cross-cultural nurse-client encounters Sample size was adequate relative to the research method and the Reserve’s population of only 600 band members. A particular strength of the study was that it yielded substantive knowledge concerning clinician behaviours that can lead to perceptions of both invalidation and affirmation among First Nations women. Findings were illustrated with many data samples. The actual health care service type and setting</p> |

(*Content in columns 3-5 was drawn from

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|--|--------------------|---------------------|--|
| both of the above written accounts of the same research study.) | | | where service was received were not identified. |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|---|---|---|--|
| <p>Bucharski, D. Reutter, L. I. Ogilvie, L. D.</p> <p>2006</p> <p>“You need to know where we’re coming from”: Canadian Aboriginal appropriate HIV counselling and testing.</p> <p><i>Health Care for Women International</i>, 27(8), 723-727.</p> | <p>Qualitative – exploratory descriptive design</p> <p>Purpose: “... was to identify Aboriginal women’s perspectives on the characteristics of culturally appropriate HIV counselling and testing.”(p. 725).</p> <p><i>n</i> = 13 women of Aboriginal heritage, aged 18 years or older who lived within 100 miles of Edmonton, Alberta.</p> <p>7/13 participated in face-to-face interviews, and the remaining 6 participated in a focus group to respond to the findings from the interviews.</p> <p>Data analysis was conducted using techniques described by Morse and Field (1995).</p> | <p>A common theme in the women’s accounts of visits to health service centres included systemic discrimination and a lack of culturally appropriate HIV testing services. Such experiences led participants to feel isolated and hesitant to access health care agency services when needed in the future. Some women avoided HIV testing services due to mistrust of strangers, cultural norms about not disclosing to outsiders, fear of being misjudged, fear of lack of anonymity and confidentiality, fear of being judged by their own community and/or fear of testing positive. When misjudged by clinicians, most women believed this stemmed from clinicians’ lack of understanding of the historical, social and cultural context within which Aboriginal women live their lives. Often resulted in health advice given that was not asked for or was inappropriate to clients’ needs and preferences.</p> | <p>Study limitations included an interview small sample size of 7 and small focus group size of 6. Also, the women were recruited from only one urban centre and were all well-educated, which would limit the transferability of the findings to other Aboriginal women of differing socioeconomic and educational backgrounds.</p> |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|--|--------------------|--|---------------------------|
| Bucharski et al. (continued) | | This study yielded important new knowledge concerning the significance of historical factors (such as colonization and residential school experiences) and to what extent the Aboriginal female client's past and present life experiences may impact upon her choices and experiences in accessing health care services related to HIV testing. | |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|---|---|--|---|
| <p>Dodgson, J. E. Struthers, R.</p> <p>2005</p> <p>Indigenous women’s voices: Marginalization and health.</p> <p><i>Journal of Transcultural Nursing, 16(4), 339-346.</i></p> | <p>Qualitative – Secondary analysis of data collected by the authors in four previous studies with indigenous women conducted during the same time period.</p> <p>Purpose: “... to describe ways in which indigenous women express experiences of marginalization related to health” (p. 340).</p> <p><i>n</i> = 57 Indigenous women aged 18-65 years of age from both rural and urban residential settings of the northern Midwest of the United States and southern Canada. These participants were originally recruited in three phenomenological and one ethnographic study that sought to gain an understanding of indigenous women’s varied life experiences.</p> | <p>Three themes were common to the analysis of data in all four of the original studies concerning women’s experiences of marginalization. These included (a) the experience of historical trauma as lived marginalization, (b) biculturalism experienced and marginalization, and (c) feeling marginalized in a complex health care system.</p> <p>Three sub-themes related to negatively perceived experiences with mainstream health services that included (a) not feeling respected by clinicians, (b) participants’ reluctance to share sensitive information with health care providers, and (c) lack of understanding by clinicians concerning the cultural ways in which Indigenous peoples make life and health decisions through consensus. Clinicians were often viewed as untrustworthy when they were abrupt, tended to not listen well, and appeared non-genuine.</p> | <p>The large qualitative sample size of 57 participants gave voice to Indigenous women’s varied experiences of marginalization within the mainstream health care system.</p> <p>However, one significant limitation of the secondary analysis design used in this study is that it did not allow for a complete exploration of the phenomenon of women’s experiences of marginalization within the mainstream health care system as the data were gathered at an earlier time and over a 5-year time span from four separate studies.</p> |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|---|--|---|---------------------------|
| <p>Dodgson & Struthers (continued)</p> | <p>Data collected over a five-year period the four previous studies were examined and specific accounts were extracted that included participants’ “experiences related to their cultural worldview and that of mainstream” (p. 341) to form a new data set as a basis for the secondary analysis. Thematic analysis was conducted using the work of Morse and Field (1995) with both researchers participating in the analysis, and resolving differences in their interpretation via discussion and consensus.</p> | <p>The researchers’ detailed discussion of the cultural differences between Indigenous and Western worldviews of health and healing yielded important insights as to how miscommunication might occur in bicultural health provider-client relationships.</p> | |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|--|--|--|---|
| <p>Garwick, A. Jennings, J. M. Theisen, D.</p> <p>2002</p> <p>Urban American Indian family caregivers' perceptions of the quality of family-centered care.</p> <p><i>Children's Health Care, 31(3), 209-222.</i></p> | <p>Qualitative and Quantitative methods using interviews and questionnaires respectively</p> <p>Purpose: To determine if urban American Indian family caregivers (of children): (1) think that children's doctors are sensitive to the caregivers' needs, (2) treat them respectfully, and to investigate the level of caregiver satisfaction as to how doctors told them about their children's medical conditions.</p> <p><i>n</i> = 30 urban Minneapolis American Indian caregivers of children with chronic illnesses</p> <p>Data were drawn from a participatory action based, multi-ethnic study (Indian Family Stories Project) using a one-to-one open-ended question interview and a three-part questionnaire with each caregiver that was derived from an original, 100-item single survey tool.</p> | <p>The majority of the participants thought that the treatment provided by clinicians was adequately sensitive to caregivers' needs. However, approximately 1/3rd of the participants felt that the health care providers did not understand the unique needs of the family and that care reflected a lack attention to these unique cultural needs. Approximately 2/5^{ths} of the caregivers felt that health care providers believed things about them that were not true and acted upon stereotypes.</p> <p>Some caregivers felt that their indirect eye contact and quiet demeanour were incorrectly interpreted by health care providers as disinterest, disrespect or a lack of education. Some health care providers did not respect family caregivers' beliefs and use of traditional healers.</p> | <p>The sample size was adequate for a qualitative study of this nature. However, the researchers did identify the small size of the survey sample and the limited urban geographical area as limitations of the study that would limit the transferability of the survey findings.</p> <p>A highlight of the study's findings was that actions taken by health practioners to provide culturally sensitive care do not only depend upon developing knowledge of American Indian health beliefs and practices. Rather, the provision of culturally competent care involved the health care providers' actual incorporation of cargivers' respective health beliefs and practices directly into the child and family plans of care.</p> |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|--|--|---|---|
| <p>Guadagnolo, B. A. Cina, K. Helbig, P. Molloy, K. Reiner, M. Cook, E. F. Petereit, D. G.</p> <p>2009</p> <p>Medical mistrust and less satisfaction with health care among Native Americans presenting for cancer treatment.</p> <p><i>Journal of Health Care for the Poor and Underserved</i>, 20(1), 210-226.</p> | <p>Quantitative design using two interview survey scales (a nine-item medical mistrust scale and a seven-item scale that measured client satisfaction with health care personnel) within a participatory action research approach.</p> <p>Purpose: “To assess barriers to cancer care among Native Americans” (p. 210).</p> <p><i>n</i> = 165 (52 Native Americans and 113 non-Hispanic Whites) (specific gender composition within each group was not specified)</p> <p>Data were collected from participants were administered prior to, or within the first two weeks of cancer treatment via face-to-face private interviews. Most of interviewers were either members of, or closely associated with the Native</p> | <p>Native Americans were significantly less likely than non-Hispanic Whites to trust health care providers. Native Americans were significantly less likely than non-Hispanic Whites to trust the health care system with health care providers than non-Hispanic Whites.</p> <p>21% of the Native Americans versus 5% of the non-Hispanic Whites agreed that they delayed getting medical care due to mistrust of doctors and nurses.</p> <p>56% of the Native Americans versus 89% of the non-Hispanic Whites agreed that the hospital or clinic they attended provided “good health care over all” (p.222).</p> <p>64% of the Native Americans versus 93% of the non-Hispanic Whites agreed that their doctor would respond with “a straight answer” (p. 222) to a posed question.</p> | <p>Strengths of the study included the use of a PAR-based approach and the determination of survey content validity of through the use of two focus groups that included Native American participants to pilot test the survey items.</p> <p>The authors acknowledged the following limitations of the study. (1) There was a significantly higher proportion of non-Hispanic Whites as compared to Native Americans within the sample composition. (2) The researchers used a survey instrument that had not been previously validated in a study situation.</p> |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|---|--|---------------------|---------------------------|
| <p>Guadagnolo et al. (continued)</p> | <p>American research communities of focus. All interviewees attended cultural competency training and were trained in the use of the survey instrument. The survey instrument was developed based upon a review of the literature and focus group meetings where the dependent variables of medical mistrust and service satisfaction were established. The independent variable was race (White /Native American)</p> | | |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|--|---|---|---|
| <p>Kurtz, D. L. Nyberg, J. C. Van Den Tillaart, S. Mills, B. Okanagan Urban Aboriginal Health Research Collective 2008</p> <p>Silencing of voice: An act of structural violence – Urban Aboriginal women speak out about their experiences with health care.</p> <p><i>Journal of Aboriginal Health</i>, 4(1), 53-63.</p> | <p>Qualitative - narrative</p> <p>Purpose: “The study explores the barriers that urban Aboriginal women face when they access mainstream health and social services and the reasons why they are increasingly seeking out these services at FCs [Friendship Centres]” (p. 56).</p> <p><i>n</i> = 13 urban Aboriginal women who access health services at three urban Indian Friendship Centres in the Okanagan Valley. (The research study reports that mainstream health care providers and policy makers are participants in the larger sample but that their responses are not reported in this preliminary report.) Data were collected from “stories and narratives that have been documented thus far” (p. 56).</p> | <p>This research report only documented the preliminary findings concerning Aboriginal women’s experiences of health services that were drawn from one of the three Indian Friendship Centres.</p> <p>Reported mainstream health service experiences of racist stereotyping (e.g., Aboriginal women are unfit mothers) and discrimination based upon health care providers’ misassumptions of alcohol and drug abuse of women with no history of substance misuse.</p> <p>Many reported that their mainstream doctors did not listen well to them and that they were not given adequate opportunities to discuss their symptoms and concerns.</p> <p>Many reported trivialization of clients’ expressed symptoms (e.g. It’s all in your head) by health care providers.</p> <p>Stories included mention of having difficulty obtaining adequate</p> | <p>A strength of this study is its ability to give voice to the less documented experiences of urban Aboriginal women.</p> <p>However, the methods of sample recruitment, data collection and data analysis were not documented in sufficient detail to adequately inform the reader.</p> |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
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| | | information about one's medical condition of the diagnosis and treatment plan of a family member. | |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|--|--|--|---|
| <p>Malach, R. S. Segel, N.</p> <p>1990</p> <p>Perspectives on health care delivery systems for American Indian families.</p> <p><i>Children's Health Care</i>, 19(4), 219-228.</p> | <p>Quantitative – survey</p> <p>Purpose: To gain a greater understanding of the barriers faced by Indigenous populations in obtaining health care services in New Mexico. <i>n</i> = 112 (Included 48 parents of children with special needs, 27 parents who were also service providers, and 37 non-Indigenous and Indigenous service providers who worked with these families.</p> <p>Data were collected using a 35 item survey that was administered in an interview format. Data analysis revealed similar responses between Indigenous parents and Indigenous parents who were also health care providers. Their combined responses were then compared with health care providers who did not have children.</p> | <p>The client/parent experience was viewed as better when services were offered in close approximation to their homes given the difficulty in accessing reliable transportation. Evening service hours were important for parents who were employed. Parents reported feeling uncomfortable in dealing with health care providers who were unfamiliar with their cultural ways. Doctors often appeared in a hurry and therefore parents were not allowed adequate time to talk about their children's problems or ask important health questions. A lack of transportation, multiple changes in staffing, a lack of specialists nearby and a lack of Indigenous physicians were seen as negative aspects of the health care experience. The authors cited a lack of available parental/family provider support services for emotional support and case management for parents.</p> | <p>Survey was developed with joint input from both Indigenous parents and non-Indigenous health care providers to promote culturally appropriate content.</p> <p>A graphic display of the findings enhanced the readability of the research findings. However, the statistical method of analysis was not clearly articulated. A response scale for the 35 item questionnaire was not disclosed. Although the survey items were co-created with a balanced team of parents and health care providers, the instrument was not pre-tested for validity or reliability in a previous study prior to use in this study.</p> |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|--|--|--|--|
| <p>Poudrier, J. Thomas Mac-Lean, R. T. 2009</p> <p>“We’ve fallen into the cracks”: Aboriginal women’s experiences with breast cancer through photovoice.</p> <p><i>Nursing Inquiry</i>, 16(4), 306-317.</p> | <p>Qualitative - photovoice</p> <p>Purpose: To explore and make visible the Aboriginal woman’s experience of breast cancer within the larger context of her life (including experiences within the health care system relative to diagnosis, treatment and follow-up support.</p> <p><i>n</i> = 12 Aboriginal women diagnosed with breast cancer in Saskatchewan who had experienced treatment within the last six months.</p> <p>Data were collected using one-to-one interview/storytelling, and photo voice.</p> <p>Interpretation of the data was based upon a feminist epistemology with a focus on visibility and power.</p> | <p>A summary of findings relevant to the breast cancer client experience within the health care system are included below.</p> <p>Health care encounters that were perceived as positive included one’s ability to develop a long-term relationship with a health care provider, and an open and honest, “straight forward and respectful communication style” (p. 314) on the part of the health care provider.</p> <p>Negatively perceived encounters included clients being the objects of racist comments. Secondly, some women felt that their own lived experiences of breast cancer within their cultural context were not understood by health care providers.</p> | <p>Multiple aspects of the research design were incorporated from the initiation of the research project to incorporate decolonizing indigenous methodologies. This included, but was not limited to, the use of a feminist theoretical foundation, the use of photovoice and storytelling, and the use of a sharing circle to promote dissemination of the findings among the participants.</p> |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|--|--------------------|--|---------------------------|
| Poudrier & Thomas Mac-Lean (continued) | | <p>Health care providers' information and advice and their expectations of clients were often incongruent with clients' lived socio-economic situations, and were not presented in ways that were culturally understandable. This left clients hesitant to ask for clarification for fear of looking uneducated.</p> <p>The study yields substantive knowledge concerning the unique experiences of Aboriginal women in Canada, in relation to having breast cancer, and their client experiences of health care services through an Indigenous cultural lens, and that this Indigenous experience of breast cancer is not well understood by health care providers.</p> | |

| Source | Purpose and Method | Main Study Findings | Strengths and Limitations |
|---|---|---|--|
| <p>Salvalaggio, G. Kelly, L Minore, B. 2003</p> <p>Perspectives on health: Experiences of First Nations dialysis patients relocated from remote communities for treatment. <i>Canadian Journal of Rural Medicine</i>, 8(1), 19-24.</p> | <p>Qualitative - descriptive</p> <p>Purpose: To explore the First Nations client experience of health and illness among dialysis patients.</p> <p><i>n</i> = 12 First Nations dialysis patients (9 females/3 males) at a hospital in Thunder Bay, Ontario</p> <p>Data were collected using face-to-face interviews and data collection was supplemented through the use of field notes. The authors briefly described their application of the “immersion/crystallization” method of data analysis based upon the work of Miller and Crabtree (1999).</p> | <p>Client separation from his/her First Nations community presented significant personal challenges for participants.</p> <p>The physical symptoms associated with the dialysis process had a significant impact on the patients’ perceived quality of life.</p> <p>All participants described how a loss of independence and restricted physical mobility resulting from their illness and hospital confinement had a significant negative impact on their sense of self-sufficiency.</p> <p>The resulting isolation from friends and family left patients feeling lonely, worrying about children and other family members at home.</p> <p>Participants struggled with feelings of uncertainty and experiences of a loss of power over their ability to make life decisions in western medical system guided by prescribed daily treatment protocols.</p> | <p>The specific philosophical foundations of the study’s approach were not stated. However, the study did employ appropriate data collection and analysis methodologies suitable to a qualitative, descriptive form of inquiry.</p> <p>The findings are significant, applicable and transferable to health care providers’ understanding of Indigenous populations in Canada given that much of complex secondary and tertiary levels of health care for First Nations persons in Canada take place at off-reserve facilities. The researchers stated that two cultural limitations of the study involved the use of a team fully composed of non-First Nations researchers and the use of a Western, rather than an Indigenous methodology.</p> |

Appendix D: Interview Protocol



The name and official logo of the First Nations Community were also included here.



Interview Protocol

Research Study Title: The Meaning of the Client Experience at a Health Promotion and Illness/Injury Prevention Health Centre within a First Nations Community in Southern Ontario

Date: _____

Interview Location: _____

Interviewer: _____

Interviewee (using code name only): _____

Interview Pre-ample Script:

I want to thank you for volunteering to be part of this research study. During our conversation today, I will be interested in listening to your views, experiences and stories as a First Nations client of the [*Name of First Nations Community*] Health Centre [*Name of Health Centre was also included in Ojibwe language here*]. Our interview will be tape-recorded so that I will have an accurate spoken account of your views, client experiences and stories to help me to correctly summarize and interpret the information that I hear. I will ask you some questions during the interview. However, I would like you to feel comfortable to talk about your views and the client experiences that are important to you. If you think of something during the interview that you want to say that may take our conversation in a different direction, please do so. Feel free to stop the interview at any time. I will begin with some general questions about your past client experiences with the Health Centre that may help to frame our discussion.

Questions:

- 1) What does health (and wellness) mean to you? What is health to you? What does being “healthy or well” mean to you?

- 2)
 - a) When you feel (“healthy, well, good”) what kinds of information or services, if any, are you likely to seek from the Walpole Island Health Centre
 - b) When you don’t feel (“healthy, well, good”) what kinds of information or services, if any are you likely to seek from the Health Centre?

- 3) Please tell me what being a client at the Health Centre has been like for you?

Further prompts:

- a) If you are comfortable in sharing, describe a specific client experience that you can remember.
 - b) Tell me more about how that experience affected you?
 - c) What did you do / how did you feel as a result of this experience?
 - d) What did you value most about this client experience at the Health Centre?
 - e) What did you value least about this experience?
 - f) How might this experience have gone better for you? – What would have needed to change about the experience to have made it more meaningful for you?
-
- 4) What suggestions do you have concerning the [*Name of First Nations Community*] Health Centre that might make your future experiences as a client of the Health Centre better or more meaningful?

Further prompts:

- a) What do you consider to be the strengths of current Health Centre programs and services?
 - b) What programs, services or other aspects of the Health Centre would you like to see changed or added in order to strengthen the client experience for Walpole community members?
 - c) Can you be more specific?
-
- 5) Is there anything more you would like to tell me?

Interview Closure Script

Thank you for taking time to meet with me today to share your views, experiences and stories. Although this interview is drawing to a close, I hope that you will meet with me again in three to six weeks. At that time, you will have an opportunity to tell me more about your client views and experiences. I may also have some different questions to ask you that emerge from the summary and analysis of our first interview conversation.

To ensure that I have accurately captured your views and experiences, you will receive a written summary of each interview to read and to make changes to if you wish. You will receive a self-addressed, stamped envelope for your use to return your comments to me.

Do you have any final questions before we part?

\$25.00 *No Frills*TM grocery store voucher accepted by participant? Yes No