

**INDIGENOUS MOTHERS' EXPERIENCES OF HEALTH CARE FOR  
INFANTS**

HOW URBAN-DWELLING INDIGENOUS MOTHERS EXPERIENCE SELECTING  
AND USING HEALTH CARE TO MEET THE HEALTH NEEDS OF THEIR  
INFANTS

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A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the  
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## **LAY ABSTRACT**

Access and use of health care are important to health and wellness. Indigenous infants are known to have poorer health outcomes than non-Indigenous infants in Canada, yet little is understood of how their parents access health care to meet their health needs. This thesis uses qualitative methods, including interviews and a discussion group, to ask Indigenous mothers living in a city about their experiences selecting and using health services to meet their infant's health needs. Interviews with health providers assist with understanding how health care is delivered to these families. The results provide important strategies for nurses and other health providers to improve how they provide care. This may then improve access to health services for Indigenous parents and ultimately lead to improved health outcomes for Indigenous infants and their families.

## **ABSTRACT**

Mothers typically act as gatekeepers to health care for their children, yet many Indigenous mothers report poor access to health services. Inadequate access to health services may contribute to the poor health outcomes experienced by Indigenous infants. Understanding how urban-dwelling Indigenous mothers experience selecting and using health services to meet the health needs of their infants is important to informing how health services can best support the needs of these families. This study employs qualitative interpretive description methodology guided by the Two-Eyed Seeing framework and Andersen's Behavioural Model of Health Services Use. Interviews facilitated by ecomaps and a discussion group were conducted with 19 Indigenous mothers living in Hamilton with infants under the age of 2 years. Additional interviews with 12 health providers added further context to the mothers' experiences. Results relate to three domains of health service use: primary care, acute care and early childhood health promotion services. Findings suggest that health providers can improve the access and use of health services by Indigenous mothers and infants through integrating three approaches to care: culturally safe care, trauma and violence-informed care and family centred care. While Indigenous-led supports may be better suited to meet the needs of Indigenous families, mainstream services can improve access and promote health service use through integrating these approaches to care. The findings have numerous implications for nursing education, practice and research as well as for health policy. Application of this evidence may result in equitable access to care, improved use of health services and better health outcomes for Indigenous infants and their families.

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## LIST OF ABBREVIATIONS

ACP	Acute care provider
ACS	Acute care services
AHAC	Aboriginal health access centres
AIDP	Aboriginal infant development program
BC	British Columbia
CAD	Canadian Dollar
CAS	Children's aid society
CASP	Critical appraisal skills programme
CI	Confidence interval
CIHR	Canadian Institute for Health Research
ED	Emergency department
FASD	Fetal alcohol spectrum disorder
FCC	Family centred care
FHV	Family home visitor
FN	First Nations
FNHA	First Nations Health Authority
HBHC	Healthy babies healthy children
HiREB	Hamilton integrated research ethics board
HIV	Human immunodeficiency virus
ID	Interpretive description
IFC	Indigenous friendship centre
LGA	Large for gestational age
LHIN	Local health integration network
Mod	Moderate
NSERC	Natural Sciences and Engineering Research Council
PCP	Primary care providers
PHN	Public health nurse
RCT	Randomized controlled trial
REB	Research ethics board
RR	Relative risk
SDoH	Social determinants of health
SGA	Small for gestational age
SIDS	Sudden infant death syndrome
SSHRC	Social Sciences and Humanities Research Council
TRC	Truth and Reconciliation Commission of Canada
TVIC	Trauma and violence-informed care
uRR	Unadjusted risk ratio

## **DECLARATION OF ACADEMIC ACHIEVEMENT**

This thesis consists of four manuscripts that have been submitted or published in peer-reviewed journals. The results of this single study are presented in three manuscripts (chapters 3-5), and separated by health service type (primary care, acute care and early childhood health promotion services, respectively). The student (Amy L. Wright) is the first author of all four of these publications and is responsible for the development of the research questions, research design, data collection, data analysis and interpretation of the findings and writing of the manuscripts and this dissertation. A research assistant, Rachel Bomberry, collaborated with the student on the data analysis and interpretation. Co-authors of the manuscripts include my supervisor, Dr. Olive Wahoush, and my thesis committee members, Dr. Marilyn Ballantyne, Dr. Chelsea Gabel and Dr. Susan M. Jack, who provided invaluable feedback on the entire research process as well as contributing to revisions in each manuscript. The dissertation and its resulting publications represent the collaborative efforts of the thesis committee and all members have given their final approval.

## CHAPTER ONE

Indigenous people in Canada experience inequitable access to health care, stemming from colonialism and resulting racist policies and funding inadequacies that directly impact their health (C. Reading, 2015). As a result, many Indigenous people in Canada experience poorer health outcomes and higher infant mortality rates than non-Indigenous people (Heaman et al., 2010; Luo et al., 2010; Smylie, Crengle, Freemantle, & Taulii, 2010). In addition, while there may be few local health services for Indigenous infants living on reserve lands in rural areas, Indigenous infants living off-reserve in urban areas where there is a greater number of health services compared to rural areas, share similar health outcomes (Heaman et al., 2010; Luo et al., 2010; Martens et al., 2010; Simonet et al., 2010).

When the need for health promotion or treatment arises, the effective access to health services is essential to promoting health and well-being. Despite this, however, very little is understood of how Indigenous mothers access and use health services to meet the health needs of their infants (A. Wright, Wahoush, Ballantyne, Gabel, & Jack, 2018). As mothers are primarily responsible for maintaining the health of their children (Norcross, Palinkas, & Ramirez, 1996; J. Wright & Fraser, 2010), this study seeks to understand how Indigenous mothers in urban areas select and use health services within the Canadian health care system. The anticipated findings will provide an understanding of how Indigenous mothers access and use health services to meet the health needs of their infants. The results will benefit health providers through providing practical ways to

adjust their care, as well as inform health service delivery and health policy that may lead to improved access to care, engagement with health services and improved health outcomes for Indigenous infants and families.

### **Research Questions**

1. How do Indigenous mothers experience selecting and using the range of health services available to meet the health needs of their infants?
2. Which factors influence a mother's selection and use of health services to care for the health of her infant?

This chapter provides an overview of the health of Indigenous people in Canada, with a focus on Indigenous mothers and infants. The impact of the social determinants of health (SDoH) on Indigenous people will be discussed, including the role of trauma. The study setting will be described, followed by the conceptual foundations of the study and its methodological considerations. Finally, the components of the dissertation will be outlined to aid reader navigation.

### **Background**

Indigenous peoples, including First Nations, Métis and Inuit, represent 4.9% of the total Canadian population (Statistics Canada, 2017) and are the fastest growing cultural group in the country. They total 1.67 million people in 2016, up from 1.1 million in 2006- four times the rate of growth for other Canadians (Statistics Canada, 2017). The researcher acknowledges that most data describing the health and wellbeing of Indigenous people has been aggregated, limiting the ability to distinguish between the unique experiences of First Nations, Metis and Inuit people. Throughout the following

dissertation, distinct groups have been identified wherever possible, as it is not the intention of the researcher to imply a pan-Indigenous lived experience. Indigenous people are young, with 9% under the age of four years; nearly one-third are younger than 14 years of age (27%); and only 4.8% aged 65 years and older (Statistics Canada, 2017). Women of childbearing age, or ages 15 to 44 years, represent 22% of all Indigenous people in Canada who are registered or hold treaty status with the government (Statistics Canada, 2018). Of note, the reliance on self-identified Indigenous ancestry and the refusal of many Indigenous people to participate in census-taking, may lead to an underestimation of these numbers (Castellano, 2004).

This study focuses on Indigenous mothers and infants living off-reserve, in the urban area of Hamilton, Ontario. In the 2016 census it was noted that 52 percent of Indigenous people live in urban areas, and more than 50% of these individuals are women (Government of Canada, 2014; Statistics Canada, 2018). Despite the increasing number of Indigenous people living in urban areas, the majority of research in Canada focuses on those living on reserve land (University of British Columbia, 2009b; Young, 2003). Therefore, research with Indigenous mothers in urban areas in Canada is of importance. This study begins to address the lack of research in urban areas<sup>1</sup>.

### **Social Determinants of Health**

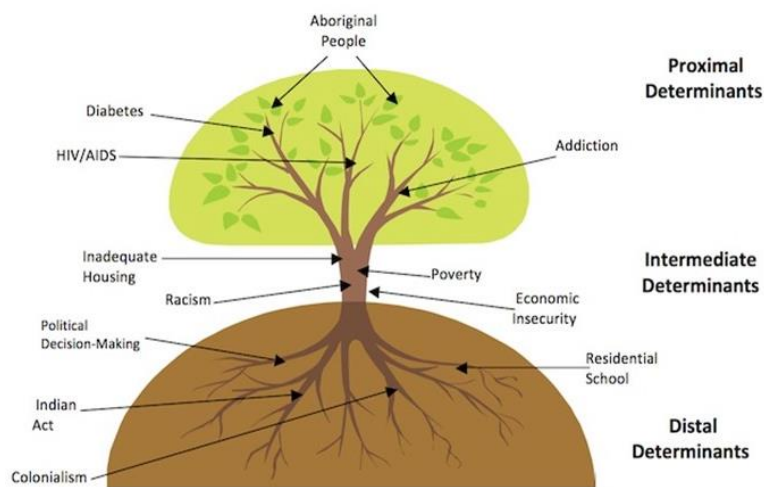
The SDoH include contextual factors such as income, employment, education, housing, etc., and are recognized as key indicators of health for individuals and communities (C. Reading, 2015). An inequitable distribution of the SDoH results in

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<sup>1</sup>See Appendix A: Operational definitions



poverty, a lack of employment, low education rates and other social issues leading to poor health outcomes (Browne et al., 2012). In an effort to conceptualize how the SDoH uniquely impact the lives of Indigenous people in Canada, C. Reading (2015) uses the analogy of a tree, where its health and condition is reflected in the impact of lower distal determinants (roots) on higher intermediate (trunk) and proximal (leaves) functions. See Figure 1: Tree diagram analogy of the SDoH affecting Indigenous people.



*Figure 1.* Tree diagram analogy of the SDoH affecting Indigenous people. Reprinted from Health Quality Ontario Quality Rounds by Muise, 2016, p. 13. Adapted from Structural determinants of Aboriginal health, Reading, 2015. In Greenwood, M., de Leeuw, S., Lindsay, N., & Reading, C. (Eds.), *Determinants of Indigenous peoples' health in Canada: Beyond the Social*. Toronto: ON: Canadian Scholars' Press. Reprinted with permission.

Distal determinants represent the foundational factors that affect the development of intermediate and proximal determinants, including historical events such as war or political ideologies (C. Reading, 2015). Distal determinants directly impact intermediate

determinants, which include health care, educational and justice systems, and government organizations (C. Reading, 2015). Distal determinants such as colonization uniquely affect Indigenous people through resulting racist and discriminatory government policies (C. Reading, 2015). This has translated into reduced funding for Indigenous programming, the over-representation of Indigenous people in the justice system and child protection services, as well as inequitable access to health care that further perpetuates inequity (Greenwood, de Leeuw, Lindsay, & Reading, 2015). Important intermediate determinants specific to Indigenous people are the land, traditional languages and ceremonies (C. Reading, 2015). These intermediate determinants subsequently influence proximal factors such as income, access to health care, culture, environment, education and other well-known SDoH (C. Reading, 2015). Inequity results in higher risks of poverty, lower education levels and poorer living conditions. Living in low-income neighbourhoods with lower social economic status, inadequate housing, overcrowding and other social conditions are all factors known to negatively influence the health of Indigenous people (Browne et al., 2016). Colonization is a SDoH recognized to uniquely impact the lives of Indigenous people, influencing determinants at distal, intermediate and proximal levels. Resulting inequities experienced by Indigenous people leads to higher risks for harm, trauma and poorer health outcomes than non-Indigenous people.

### **Trauma**

Trauma is known to have a negative impact on health, including altering stress responses that lead to an increased risk of depression, post-traumatic stress disorder,

substance use as a coping mechanism, and a number of long-term chronic diseases (Bombay, Matheson, & Anisman, 2009). Indigenous people are at risk for experiencing trauma at distal, intermediate and proximal levels of the SDoH. When individuals experience an event they do not expect or cannot control, it can trigger feelings that surpass one's ability to cope, and trauma can be experienced as a result (Manitoba Trauma Information Centre, 2018a). Trauma exists in numerous forms, some of which may include; (a) interpersonal, (b) external, (c) historical and (d) developmental (Manitoba Trauma Information Centre, 2018b). For Indigenous people, trauma can also be (e) intergenerational (Bombay et al., 2009). Interpersonal trauma takes place between individuals, including all forms of abuse, suicide, and the historical trauma realized by Indigenous people due to the lasting effects of colonization (Manitoba Trauma Information Centre, 2018b). External trauma results when an individual is negatively impacted by outside forces, such as war, crime or death of a loved one (Manitoba Trauma Information Centre, 2018b). Events relating specifically to a particular cultural group, such as the Holocaust and its traumatic impact on Jewish people, or the residential school legacy and its associated trauma for Indigenous people, are known as sources of historical trauma (Manitoba Trauma Information Centre, 2018b). Trauma that occurs while a child is developing and maturing is referred to as developmental trauma (Manitoba Trauma Information Centre, 2018b). Intergenerational trauma refers to the continued impact of past trauma, which can be passed on to children and affect their health and well-being (Bombay et al., 2009).

Many Indigenous people face ongoing interpersonal trauma from racism and discrimination. Research investigating the health impacts of race-based traumas reveals lower engagement in what are seen as protective activities - such as ceremonies and traditional activities – and are associated with higher rates of alcohol use and suicide (Fast & Collin-Vézina, 2010). Indigenous women are at a high risk of experiencing interpersonal trauma resulting from violence, which they are three times more likely to experience in their lifetime compared to non-Indigenous women (Amnesty International Canada, 2014). They also experience violence more often, and with greater severity (Amnesty International Canada, 2014). Women who experience violence are more likely to live in precarious situations, increasing their risk of homelessness, and poverty (Amnesty International Canada, 2014). Experiences of violence have been shown to influence health-seeking behaviours, as women may be frightened to disclose their history of abuse to health providers; they may feel judged and/or shame about their situations (Catallo, Jack, Ciliska, & MacMillan, 2013).

Social and political policies that result in inequities causing harm are examples of external trauma and structural violence (Browne et al., 2012). At government and organizational levels, modes of structural violence are represented in health care, judicial and child welfare policies (among others) that disproportionately disadvantage Indigenous people. They are sources of ongoing trauma and harm that can lead to poverty, inequitable access to health care, homelessness and experiences of racism and discrimination (Browne et al., 2012).

All Indigenous people in Canada live with the historical trauma caused by colonialism. The arrival of Europeans resulted in forced relocation and an end to their traditional governance structures, lifestyles, cultures, and ceremonies (The Truth and Reconciliation Commission of Canada, 2012). European settlers to North America brought foreign diseases with them that consequently caused the death of millions of Indigenous people (Shroff, 2011). In 1876, the Indian Act provided legal definitions and parameters pertaining to Indian status, band rights, and Indian reserves (University of British Columbia, 2009a). First Nations people on the Indian Register were considered legal “status” Indians, entitled to certain government benefits and forced to live on reserve lands (University of British Columbia, 2009a). Many are also affected by collective trauma, or the common, collective experience of trauma felt by entire communities and Indigenous people (Bombay et al., 2009). Among other historically traumatic experiences, the residential school system and the sixties scoop were particularly damaging (The Truth and Reconciliation Commission of Canada, 2015). The residual and long-lasting effects influence stress responses and coping mechanisms. They have also been associated with other comorbidities, including mental health issues such as anxiety, depression and post-traumatic stress disorder, as well as physical ailments that include heart disease (Bombay et al., 2009).

Research with Holocaust Survivors has demonstrated that historical trauma has biological influences on offspring, including negatively affecting parenting styles and their ability to attach to their children (Bombay et al., 2009). The impact has been shown to have intergenerational effects, continuing on to children and grandchildren of survivors

(Bombay et al., 2009). As Indigenous people attempt to cope with their experiences, children are uniquely impacted by intergenerational trauma - also known as developmental trauma in this instance - that influences health outcomes over generations, including an increased incidence of drug and alcohol abuse (The Truth and Reconciliation Commission of Canada, 2015). A lack of positive parental role-models in residential schools led to problematic attachment and parenting amongst some Indigenous families, putting children further at risk for developmental trauma (The Truth and Reconciliation Commission of Canada, 2015). Indigenous people are susceptible to experiencing trauma in its various forms, which adds to the effect of inequitable access to health care and negative health outcomes. Despite these risks, however, Indigenous people remain resilient, fighting for equitable access to care and recognition of their beliefs and values in mainstream health systems.

### **Health Funding**

Health funding represents an intermediate determinant of health that has unique and negative impacts on the access and use of health services by Indigenous people. First, provincial funding ensures access to hospitals and health care to all Canadians, including Indigenous people, but excludes health care on reserve land (Health Canada, 2012). Health care on reserves is financed federally and consists mainly of primary care services provided by various Indigenous-led programs (Health Canada, 2012). Federal funding covers additional non-insured health benefits, including vision and dental care, but only to First Nations and Inuit people with government Indian status (Health Canada, 2012). Those who do not have Indian status do not share these same health funding benefits.

Important changes in Canadian funding models and policies have shaped approaches to how more equitable health services are provided to Indigenous people, regardless of whether they live on or off reserve. First, Ontario's Aboriginal Health and Wellness Strategy developed in 1994 combined Indigenous and mainstream programs and services to improve Indigenous health (Ministry of Community and Social Services, 2010). This initiative resulted in the development of several Indigenous-led health services, including Aboriginal Health Access Centres (AHAC). These serve as entry points for primary care services, Indigenous Healthy Babies, Healthy Children programs, healing lodges, shelters, family violence healing programs and crisis intervention teams (Ontario Ministry of Children Community and Social Services, 2018). Second, the province of British Columbia (BC) is unique in that it replaced the federally-run Non-Insured Health Benefits program and established its own Indigenous-run First Nations Health Authority (FNHA) (First Nations Health Authority, 2016). The FNHA provides extended health benefits for Indigenous residents of BC with Indian status (First Nations Health Authority, 2016). Third, Jordan's Principle was developed in response to Jordan River Anderson, a First Nations child who died in hospital at the age of five, where he waited almost two years for the province and federal government to make a decision on who was responsible to pay for his at-home health care services (Blackstock, 2012). Jordan's Principle states that a child's needs must be put ahead of jurisdictional disputes between federal and provincial governing bodies and payment for services; that health care be provided as required, and that payment of services is determined later (Blackstock, 2012). This example demonstrates the complexity of health funding for First

Nations people, and how gaps that may occur in health care provision can cause unnecessary pain and suffering. While these initiatives fall short of providing equitable health care for all Indigenous people in Canada, they are an encouraging sign of government beginning to respond to health inequities.

### **Health Outcomes**

The impact of an inequitable distribution of the SDoH, largely stemming from colonialism, continues to put Indigenous people at risk for poor health outcomes. Indeed, many Indigenous people experience higher rates of diabetes, arthritis, infectious diseases, suicide, and mortality than non-Indigenous people (Reading & Wien, 2009; Reading & Halseth, 2013; Smylie, Fell, Ohlsson, & Joint Working Group on First Nations, Indian, Inuit and Métis Infant Mortality of the Canadian Perinatal Surveillance System, 2010). Indigenous children in residential schools suffered poor nutrition and a lack of traditional meals and foods. As a result, the health benefits and knowledge of healthy eating and traditional food preparation has been lost for some, yet others are fighting to regain these traditions (The Truth and Reconciliation Commission of Canada, 2015).

As previously discussed, Indigenous women face higher risks of health disparities than non-Indigenous women including poverty, inadequate housing, higher rates of diabetes, HIV, substance use and violence (Van Herk, Smith, & Andrew, 2011). They are more likely to single parent, almost twice as likely to smoke than non-Indigenous women and are at a higher risk for gestational diabetes and hypertension (J. Reading, 2009). Maternal smoking and gestational hypertension are associated with low birth weights, and these babies may subsequently develop poor growth, development and anemia (Tarlier,



Johnson, Browne, & Sheps, 2013). These infant health conditions can lead to learning difficulties, motor and cognitive delays and increased rates of hypertension and diabetes in later life (Tarlier et al., 2013). Gestational diabetes is also associated with larger birth weight infants which can result in neonatal hypoglycemia, birth injuries due to the need for instrumentation at birth, as well as increased risks of type two diabetes and cardiovascular disease later in life (Sayers, 2009; Tarlier et al., 2013).

Indigenous infants have significantly higher rates of birth complications and infant mortality rates than non-Indigenous infants (Heaman et al., 2010; Luo et al., 2010; Smylie et al., 2010). They are more likely to require admission to hospital than non-Indigenous infants as a result of higher rates of ear infections, respiratory diseases, injury, meningitis, and other conditions (Johnson, Jin, & Truman, 2002; Smith, Edwards, Varcoe, Martens, & Davies, 2006; Van Herk et al., 2011). First Nations infants and toddlers also have significantly lower immunization rates than other non-Indigenous children, though rates vary and data is conflicting (Tarlier et al., 2013; A. Wright et al., 2018).

Reserve communities located in rural areas typically lack health services, adequate housing, employment and educational opportunities (Heaman et al., 2010; Jenkins et al., 2003; National Aboriginal Health Organization, 2009; Pampalon, Martinez, & Hamel, 2006). Conversely, urban communities boast numerous health services, employment and educational opportunities and better housing, yet the related potential benefits to health for Indigenous people are not realized; health outcomes for Indigenous infants born in urban areas remain similar to those born on-reserve in rural areas (Heaman et al., 2010; Luo, Wilkins et al., 2010; Martens et al., 2010; Simonet et al., 2010).

### **Access to Health Services**

Indigenous people in Canada experience poor access to health services (Gao et al., 2008; Martens, Sanderson, & Jebamani, 2005). Even with increasing migration to urban areas, poor access to health care persists (Snyder & Wilson, 2012). In a study by Gao et al. (2008), Indigenous people were almost twice as likely as non-Indigenous people to be admitted to hospital for a condition that could have been addressed earlier by preventative outpatient or primary care services. Access to primary health care is especially important as it has been linked to improved health outcomes and a reduction in health inequities (Van Herk, Smith, & Tedford Gold, 2012).

The literature suggests there is complexity in accessing health services, and that access is a culmination of numerous factors. Using Anderson's *Behavioral Model and Access to Medical Care* as an exemplar, variables known to impact one's access to health care include (a) the environment (health care system, external environment), (b) population characteristics (predisposing characteristics, enabling resources, need), (c) health behaviour (personal health practices, use of health services) and (d) outcomes (perceived health status, evaluated health status, consumer satisfaction) (Andersen, 1995). Andersen's model has been extensively tested and validated in its various forms with diverse ethnic populations, including Indigenous people in both Canada and Australia, and in various health care contexts (Andersen & Davidson, 1997; Babitsch, Gohl, & von Lengerke, 2012; Nabalamba & Millar, 2007; Trinh & Rubin, 2006; Wallace & Macentee, 2012). The *Behavioral Model and Access to Medical Care* version has been most extensively validated in the literature, as it recognizes the importance of consumer

satisfaction in health care access, and the influence of each variable on another (Andersen, 1995).

First, environmental factors, including the availability of AHACs in Ontario and specialty services, such as counseling, mental health services, parenting classes, and traditional midwifery have been demonstrated to improve access to health care for Indigenous people (Benoit, Carroll, & Chaudhry, 2003; Bucharski, Reutter, & Ogilvie, 2006; Environics Institute, 2010; Newbold, 1998; Van Herk et al., 2012). The availability of health care services in communities improves access for Indigenous people, as travel outside one's immediate community causes concerns regarding transportation costs and about feeling vulnerable by being in unknown areas (Browne et al., 2011; McCall, Browne, & Reimer-Kirkham, 2009; Tjepkema, 2002).

Second, population characteristics, such as the presence of poverty, inhibits access to health care. Costs associated with transportation fees to attend services, childcare and extended health benefits, including drug coverage or dental care, are described as prohibitive (Browne et al., 2011; Environics Institute, 2010; Levin & Herbert, 2004; McCall et al., 2009; Senese & Wilson, 2013). In addition, only Indigenous people with Indian status receive some extended health benefit coverage from the government, yet these provisions are experiencing funding cuts (Senese & Wilson, 2013; The Truth and Reconciliation Commission of Canada, 2015).

Third, the health behaviours of individuals has been demonstrated to impact health care access. With barriers to primary care services, Indigenous people use acute care services such as the emergency department (ED) more often than non-Indigenous people

(Browne et al., 2011; Smylie et al., 2011). Indigenous children also attend the ED more frequently than non-Indigenous children, and rarely require admission for their health complaints. This suggests that most issues could have been managed by primary care services (Canadian Institute for Health Information, 2015).

Very little is understood of the health behaviours of Indigenous mothers caring for the health of their infant. What is known is related to immunization uptake and oral health, reflecting only the behaviours of those living on-reserve (A. Wright et al., 2018).

Finally, within the outcome variables of Andersen's model (1995), the health status of individuals influences one's access to care. The presence of maternal depression has been demonstrated to increase children's use of acute care services (Guttmann, Dick, & To, 2004). Negative health care interactions that stem from experiences of racism, discrimination and judgmental care reduces consumer satisfaction and is known to influence the way Indigenous people access health care (McCall et al., 2009; Senese & Wilson, 2013; Tang & Browne, 2008; Van Herk et al., 2011, 2012). When people felt discriminated against, they were more likely to delay accessing treatment until their health had significantly deteriorated, or not access it at all (Denison, Varcoe, & Browne, 2013; Kurtz, Turner, Nyberg, & Moar, 2014). How maternal mental health, discrimination or racism collectively influences the access of health services for Indigenous mothers caring for the health of their infants is not known.

Health service access is important for a child's health because it is associated with a reduction in infant mortality (Brandon, Costanian, El Sayed, & Tamim, 2016). In addition, research suggests that the disadvantage experienced by infants and toddlers has

a lasting effect on a child's development, self-worth and intellect (Lloyd, Li, & Hertzman, 2010; Nguyen, 2011). Hertzman (2000) argues that specific biological and developmental processes are impacted during fetal life and early infancy, and that events during these sensitive periods can have life-long health impacts. For example, an infant's weight at one year of life has been associated with heart disease later in life (Hertzman, 2000). Similarly, children with delayed growth and limited developmental opportunities such as exposure to reading, reported poorer health in later life compared to those with typical normative growth rates who were exposed to reading when they were young (Hertzman, 2000). These findings suggest that interventions aimed to improve the health of infants will subsequently promote health in adulthood and provide potential benefits for society as a whole (Hertzman, 2010). Therefore, developing an understanding of how Indigenous mothers living in urban settings experience using health care for their infants has the potential to make a significant contribution to many families and their communities.

### **Criteria for Choosing Hamilton**

Hamilton has been selected as the setting for this study due to the high number of Indigenous mothers and infants living in the city. Hamilton sits on the traditional territories of the Haudenosaunee and Mississauga nations (Smylie et al., 2011), and is uniquely situated close to two First Nations reserves; the Six Nations of the Grand River and the Mississaugas of the New Credit. The Six Nations of the Grand River represents the largest reserve in Canada in terms of population and the second largest reserve in the country in terms of land mass (Six Nations of the Grand River Development Corporation,

2018). Nearly 27,000 individuals hold membership there and almost 13,000 people live within its borders (Six Nations Council, 2017).

**Health services in Hamilton.** Hamilton is a census metropolitan area, and home to approximately 721,000 individuals (Statistics Canada, 2015b). It is located in the Local Health Integration Network (LHIN) Zone 4, which aside from Hamilton, also services Niagara, Haldimand and Brant counties (Provincial Council for Maternal and Child Health, 2016). The city has four tertiary level hospitals: a cancer centre, a full array of primary care and specialty services, as well as an Aboriginal Health Access Centre in the downtown. There are also several organizations providing Indigenous-led early childhood health promotion services including the Hamilton Indigenous Friendship Centre, and the Ontario Native Women's Association (The Health Line, 2015).

**Demographics.** Hamilton has a population of 721,000 of which approximately 84% is aged 15 years or older, with the average age of 41, and 5.3% are children aged four years and younger (Statistics Canada, 2015b). Visible minorities account for approximately 14%, with over 12,000 people identifying as Indigenous (Statistics Canada, 2015b). Of those, 9300 claim First Nations identity, 2100 claim Métis identity, and 720 claim other Indigenous identity (Statistics Canada, 2015a).

Indigenous children aged 14 years and under make up 2.8% of all children in Hamilton (Statistics Canada, 2015a). A larger proportion (27.8%) of Indigenous people are children aged 14 years and under, compared to 16.8% of the same age group for non-Indigenous people in Hamilton (Statistics Canada, 2015a).

A survey by Smylie et al. (2011) provides us with our best understanding about what is known about the health of First Nations people living in this city. Data were obtained from more than 700 First Nations participants. Of those who responded, 78.2% reported an annual income less than \$20,000 CAD, and 70% reported living in the lower income quartile neighbourhoods, compared to only 25% in the general population of Hamilton (Smylie et al., 2011). Thirteen percent of survey respondents reported being homeless, living in transition, or in another type of dwelling not listed as typical living arrangements on the survey, and almost three-quarters of respondents (73.7%), reported living in crowded conditions compared to only 3% in the general Canadian population (Smylie et al., 2011). Participants reported three times the rate of diabetes, and nine times the rate of hepatitis C, as well as higher rates of hypertension than the general Hamilton population (Smylie et al., 2011). In addition, more than 30% of respondents reported their mental health as fair or poor, or that they are living with a mental health disorder (Smylie et al., 2011). Respondents reported visiting an ED more than twice as often as others living in Hamilton, and 44% rated the quality of this care as only fair or poor (Smylie et al., 2011). Parents reported high rates of asthma, allergies, and chronic ear infections in their children aged less than 14 years (Smylie et al., 2011). Although most children were seen by a physician or pediatrician in the past year (83%), more than half reported concerns about their child's physical (56%) and mental/intellectual health (38%), as well as their emotional (54%), speech/language (41%), and social development (25%) (Smylie et al., 2011). Parents of children aged five years or less, reported their children's health as only fair (4.6%) or poor (0.7%) (Smylie et al., 2011). Despite parental concern for their

child's health and development, 55% reported that their children had not participated in culturally appropriate early childhood health promotion services available in the community (Smylie et al., 2011). These findings suggest that many First Nations people living in urban Hamilton experience health disparities, have concerns about the health and development of their children, and do not participate in culturally appropriate, early childhood health promotion programming, despite the availability of these services.

In summary, the limited research of urban areas with Indigenous people, coupled with the large number of Indigenous people and proportion of Indigenous infants living in Hamilton makes this city an optimal setting for understanding how Indigenous mothers select and use health services to care for the health of their infants.

## **Conceptual Foundation**

### **Philosophical Paradigm**

This research study is grounded in the constructivist paradigm, valuing the presence of multiple realities constructed through subjective experiences and interaction with the natural environment, as well as the belief that knowledge exists in many forms (Appleton & King, 1997). While the researcher intends for the research to also be grounded in Indigenous ways of knowing through the application of Two-Eyed Seeing (as discussed later), this is not fully attainable without Indigenous lived experience. To address this need, Indigenous mentors and advisors were involved in this work to ensure it stayed as true to Indigenous ways of knowing as possible with a non-Indigenous researcher. Although Indigenous ways of knowing are distinct from Western philosophies, including constructivism, they tend to agree with constructivist approaches



to ontology and epistemology (Koster, Baccar, & Lemelin, 2012; Kovach, 2009; Loppie, 2007). Indigenous worldviews generally acknowledge the presence of multiple truths, the co-construction of knowledge through relationships and interactions with others, and value non-Western forms of knowledge systems such as language, art, spirituality, ceremony and more (Bartlett, Marshall, Marshall, & Iwama, 2012, Smith, 1999). While Indigenous research methodologies were considered at the outset of this work (Kovach, 2009, Smith, 1999), it was concluded that a methodology consistent with a specific nation's traditions, beliefs and ways of knowing could not guide the research as it required inclusivity of First Nations, Métis and/or Inuit participants. In addition, as the researcher does not have lived experience as an Indigenous person, the Two-Eyed Seeing framework was used, as it allowed for the respectful coming together of both Indigenous and Western knowledges.

### **Two-Eyed Seeing**

Two-Eyed Seeing provides an overarching philosophical perspective to the research that has shaped the development and implementation of the study since inception. Originally introduced by Mi'kmaq Elders, Albert and Muerdena Marshall, from Cape Breton, Nova Scotia, Canada in 2004, Two-Eyed Seeing stresses the importance of viewing the world through both Western (mainstream) and Indigenous worldviews (Bartlett et al., 2012). Two-Eyed Seeing was initially presented at Cape Breton University to encourage Indigenous students to pursue science by including both Indigenous and mainstream ways of knowing in science curricula (Bartlett et al., 2012). Since then, its use as a guiding framework for education as well as in research with

Indigenous people has been advocated by numerous organizations and institutions, including the Canadian Institute for Health Research (CIHR), the Natural Sciences and Engineering Research Council (NSERC) and the Social Sciences and Humanities Research Council (SSHRC) (Bartlett et al., 2012). Two-Eyed Seeing stresses the importance of viewing the world through one eye using the strengths of Indigenous worldviews, and with the other eye using the strengths of Western worldviews, to see together with both eyes to benefit all (Bartlett, Marshall, & Marshall, 2012). A weaving of perspectives is emphasized, with both having equal importance, but in some instances one perspective furthering our understanding of a specific concept or situation more than the other (Bartlett et al., 2012).

Within a research context, researchers are encouraged to learn how to weave back and forth between Indigenous and Western ontologies, epistemologies and methodologies as required. The authors use a visual of two jigsaw pieces intersecting, one not having a larger portion of the “big picture” than the other, but both having equally important perspectives (Bartlett et al., 2012). Also emphasized is the need to involve Indigenous Elders during data analysis to ensure the incorporation of traditional knowledge is authentic (Bartlett et al., 2012). They also stress that not only should Elders be approached for their perspectives, but other knowledge holders with different perspectives should be consulted, which can lead to a better understanding of the phenomenon under study (Bartlett et al., 2012).

The developers of Two-Eyed Seeing have visually depicted their views of four “big picture” philosophical questions, including integrating ontology, epistemology,

methodology, and overall knowledge objectives (Institute for Integrative Science & Health, n.d.). In the first, Indigenous ontology is depicted as interconnective and animate, consisting of a constant balance between spirit, energy and matter; while Western ontology is depicted as objects consisting of their parts and wholes, in constant evolution (Institute for Integrative Science & Health, 2013). In the second, Indigenous epistemology is described as relational, respectful and reciprocal; while Western epistemology is based on hypothesis and theory construction (Institute for Integrative Science & Health, 2013). In the third, Indigenous methodologies consist of a weaving of patterns within nature, and relationships among love, land and life; while methodologies in Western science tend to unravel nature's patterns to understand them and to build models to explain the interactions of their components (Institute for Integrative Science & Health, 2013). Finally, objectives or goals from Indigenous perspectives are collective, with the purpose of understanding and sustaining the environment; while Western goals tend towards what is testable and constructible, to understand how the world works (Institute for Integrative Science & Health, 2013). A thorough review of how Two-Eyed Seeing has been defined and carried out in the literature to date is explored in Appendix B: Two-Eyed Seeing integrative review.

### **Disciplinary Orientation**

The researcher's nursing orientation provides another lens with which to view this study. Certainly, the motivation to initiate this work results from a nursing lens that considers inequitable access to health care and poor health outcomes of marginalized groups as unacceptable. The influence of this perspective on the research has been noted

throughout the scaffolding exercise that follows and will be analyzed throughout the chapters of this dissertation.

### **Scaffolding**

As noted within methodological foundations below, this study employs Interpretive Description, described by Thorne (2008), as a guiding methodological framework. Prior to embarking on a research study, Thorne (2008) suggests that the researcher first reflect on who they are, what they represent, and what they are trying to accomplish, terming this process “scaffolding” (Thorne, 2008). In undertaking this process of reflection, Thorne (2008) suggests the researcher ensures the study is built upon a firm and sturdy foundation of one’s intellectual and philosophical beliefs. Sharing one’s background, beliefs, values and ancestral history is also in line with Indigenous ways of knowing and research philosophies (Lavallée, 2009). Sharing these reflections with the reader grants the opportunity to understand from which worldview one is speaking (Lavallée, 2009). Therefore, the following represents a reflection on the writer’s background, beliefs and values as a researcher to fulfill the scaffolding aims as suggested by Thorne (2008), and to help in establishing trusting relationships with readers and the Indigenous community at large.

#### **Reflection of the Researcher**

I am a non-Indigenous researcher and nurse practitioner of European settler descent. As a non-Indigenous individual raised in Canada, I acknowledge my upbringing as having been dominated by Western mainstream culture, and therefore acknowledge my Western biases. I acknowledge the presence of a dominant Western model of society in

Canada, and the need for society to disengage from feelings of Western superiority (Ermine, 2007). Ermine (2007) describes the exchange between individuals of differing cultural backgrounds as ethical space, where members from other cultures recognize their differences (traditions, beliefs, values), but choose to step out of these loyalties to meet another in a person-to-person exchange that is to the ethical benefit of both.

Consequently, through this study, I seek to engage in ethical interactions between members of Indigenous and Western cultures in Canada.

I acknowledge my nursing values and beliefs, including my desire to understand the lived experience of others, in order to improve and individualize nursing care and promote optimal health outcomes (Thorne, 2008). Nursing cannot be defined merely by a knowledge base situated in the physical and social sciences, but must also take into account its fundamental obligation to use knowledge for the betterment of humankind (Barrett, 2002). As such, nurse researchers seek knowledge to benefit the nursing profession, as well as to promote the health of clients and patients (Barrett, 2002). Unlike other science disciplines, a nurse's thirst for knowledge is for the purpose of bettering our profession through *doing*, rather than simply by knowing (Grace & Perry, 2013). Through practicing reflexivity, I examine my beliefs and values and the influence they may have on the research process.

Situated in nursing science, I take a holistic view of an individual's health, acknowledging the importance of physical, mental, emotional and spiritual elements. Taking a constructivist philosophical stance, I acknowledge the presence of multiple realities in human experience. As a nurse researcher, I seek to both understand individual

experiences, as well as to determine similarities in experience, so that nursing care can benefit the individual as well as the collective.

Finally, I hope to be viewed as an ally to Indigenous people, supporting and advocating for Indigenous self-determination, equality in health and well-being and promoting culturally-safe healthcare. I wish to be more than a temporary support to Indigenous people in their fight against colonization, I hope to be an accomplice in the movement, fighting alongside Indigenous partners in a long and lasting relationship (Fornssler et al., 2018).

### **Methodological Foundations**

This study employs a qualitative interpretive description research design. Qualitative research approaches are useful in providing a holistic perspective on a particular phenomenon of interest related to the human experience (Creswell, 2007). Using language, the researcher describes and critiques the phenomenon to further understand its elements and complexity (Creswell, 2007). Qualitative studies are necessary when little is known of a phenomenon, thus requiring its thorough exploration before variables might be identified for use by alternative quantitative methods. As demonstrated in the literature previously, very little has been explored relating specifically to how Indigenous mothers engage with health care services to meet the health needs of their infants. Consideration of contextual factors and how they shape daily living is particularly important in research with marginalized persons. Multiple factors such as historical trauma, residential school experiences and marginalization must be considered, as these factors shape the life course of Indigenous peoples. For these

reasons, qualitative research methodology was used to explore the phenomenon of Indigenous mothers engaging with the Canadian health care system to meet the health needs of their infants, including primary care<sup>2</sup>, acute care<sup>3</sup> and early childhood health promotion services<sup>4</sup>.

### **Interpretive Description**

Interpretive description (ID) methodology, as described by Thorne (2008, 2016), guides this study, providing direction on study design and motivation for its pragmatic use in health care. Nurse researchers seek knowledge to improve the ability of the discipline to impact individual and community health and well-being, and while traditional methods such as ethnography, grounded theory and phenomenology develop theoretical insights, they are not always able to expand the knowledge needed for practical application (Thorne, Stephens, & Truant, 2015). Interpretive description is amenable to guiding philosophical assumptions that further the research and lead to solutions that can positively impact the health and well-being of others (Thorne, 2008, 2016). The methodology was developed by nurse researchers as an alternative approach to qualitative methods that were rooted in the traditions and philosophies of the social sciences (Thorne, 2016). By comparison, ID has been developed specifically to understand and address applied health issues. Based on a nursing epistemology and

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<sup>2</sup> Primary care refers to the community-based comprehensive provision of health promotion and treatment of illness and disease (Canadian Nurses Association, 2015).

<sup>3</sup> Acute care refers to care provided for urgent and life-threatening health conditions (Canadian Institute for Health Information, 2018). In many cases, acute care services are accessed when primary care clinics are closed or unavailable.

<sup>4</sup> Early childhood health promotion services refer to programs and services available to support parents in forming healthy attachments with their infants, effective parenting skills and promoting the healthy growth and development of infants.

disciplinary goals, ID emphasizes the development of useable knowledge that can have practical application for clinicians (Thorne, 2016). The approach is philosophically grounded in constructivism and naturalistic inquiry, which respects the infinite variation in human experience, and the influence on each by a range of contextual factors (Thorne, 2016). Through the use of ID, this study seeks to develop knowledge beyond a mere description of themes, by uncovering relationships and patterns in the data, that can challenge the way we view the phenomenon, and offer the potential for clinical application (Thorne, 2016).

**Methodological integrity.** Thorne (2016) suggests that the use of ID in the applied health sciences, and the inevitable influence of study results on people, requires the researcher to consider a unique set of quality standards. These include epistemological integrity, representative credibility, analytic logic, interpretive authority, moral defensibility, disciplinary relevance, pragmatic obligation, contextual awareness and probable truth (Thorne, 2016). A description of each and their application to the study now follows.

**Epistemological integrity.** First, epistemological integrity was maintained by ensuring the research question, process and findings were aligned with the assumptions of ID (Thorne, 2016). Through the research questions and data collection techniques, this study uncovered a thorough understanding of these factors and their influence on the phenomenon. Similarly, recognizing the influence of the researcher on the data and study results, reflexivity was practiced by the researcher throughout the research process.



Finally, the resulting dissertation reflects the philosophical tenets from which it originated, demonstrating its epistemological integrity.

**Representative credibility.** Study conclusions are congruent with the sampling techniques employed, demonstrating representative credibility. Conclusions are presented based on the experience of Indigenous mothers living in urban Hamilton, without assuming the experience of other mothers. Data were also collected from interviews with health providers to provide additional contextual information to compliment and expand on the experiences shared by mothers. The reader must determine whether results from this study can be applied to other populations. Second, a thorough understanding of the phenomenon has been obtained. Later interviews and the discussion group were used to fill gaps in knowledge and to confirm the presence and details of the themes. See Appendix C: Sample Interview Guide. The application of Two-Eyed Seeing (Bartlett et al., 2012) has contributed to relatable and useable knowledge for both Indigenous and non-Indigenous people in relation to Indigenous mothers caring for their infants. The use of a research advisory group during data analysis ensured both worldviews were adequately and appropriately applied. Finally, data sources were triangulated by concurrent collection and analysis, collaborative data analysis with the research assistant, confirmation with the participants during the discussion group and by aligning the findings with those expressed by health professions, as well as those available in the literature. The use of triangulation assists the researcher in confirming the presence of concepts and the relationships between them, adding to the study's representative credibility (Guba, 1981).

**Analytic logic.** Thorne (2016) explains the concept of analytic logic to include the presentation of sound and logical decision-making throughout the research process. To ensure this study was conducted in a way that demonstrated analytic logic, several strategies were employed. First, the rationale for the research question and methodology were clearly presented, with supporting rationale from the literature. Second, methodological considerations were clearly described throughout the dissertation. Third, the research advisory group helped the researcher ensure decisions were made in logical ways that were in line with the research methodology and its philosophical underpinnings. Fourth, an audit trail consisting of a reflexive journal and numerous analytic memos provided a guide to the research process. Finally, findings were presented with quotes from the participants, enabling the reader to confirm the presence of themes and concepts for themselves.

**Interpretive authority.** The concept of interpretive authority can be described as the need for the reader to be assured that the researcher's findings are trustworthy, and external to their own beliefs and biases (Thorne, 2016). As suggested by Hutchinson and Wilson (1992), steps were taken to ensure the data collected during interviews were valid and credible, and reflected the purpose of the research study. First, interview questions were carefully developed to reflect only the purpose of the research, and not unrelated topics. Next, rapport was built with the community and key stakeholders over several years prior to initiating the research. The researcher and research assistant attended community and mother/baby events to establish rapport with the participants. This has been found to put participants at ease, allowing for more accurate and detailed

information to be shared (Hutchinson & Wilson, 1992). A reflexive journal detailed the researcher's biases, beliefs and preconceived assumptions, as well as their possible influence on the research process. Finally, member checking occurred during the discussion group, returning to participants to confirm and clarify concepts and themes. The use of member checking was essential to ensure the researcher's interpretations were valid in the absence of Indigenous lived experience.

**Moral defensibility.** Researchers in the applied health sciences uniquely aim for their studies to benefit others and promote health and wellness (Thorne, 2016). Indeed, the benefit of research for the patients should outweigh the risks of undertaking the research in the first place (Thorne, 2016). This study uncovered knowledge that can be used to improve health service delivery. Improved health service delivery might ultimately lead to improved health outcomes for Indigenous mothers and infants.

**Disciplinary relevance.** The purpose of this study was relevant to nursing and an appropriate issue to be examined within the context of nursing science. It can therefore be said to have disciplinary relevance. Population health is certainly a subject of nursing inquiry, as is the influence of the SDoH on health behaviour and health outcomes. This is evidenced by the following: Ontario's First Nations Health Action Plan and its commitment to improving access to health services for Indigenous people, by the partnership between Canadian Nurses Association and the Canadian Indigenous Nurses Association, aimed at improving health outcomes of Indigenous people, and by the Calls to Action outlined by the Truth and Reconciliation Commission of Canada (Canadian

Nurses Association, 2016; Ministry of Health and Long-Term Care, 2016; The Truth and Reconciliation Commission of Canada, 2015).

**Pragmatic obligation.** Thorne (2016) stresses the importance of applied health researchers to consider the impact of their research findings on practice. She suggests that due to the nature of clinical work, regardless if the intent of the findings was merely to be theoretical, or to be confirmed through additional testing, findings are at risk of being applied to patients before they can be determined to be true (Thorne, 2016). As such, it is imperative for the researcher to clearly articulate which findings might be applied to patients, and which are areas for future work. Careful attention to pragmatic obligation has been made to the wording of findings, particularly those in publications that will be widely disseminated.

**Contextual awareness.** Although the researcher makes every attempt to account for how preconceived beliefs and assumptions may influence the research process and results, Thorne (2016) stresses that the results will still be influenced by invisible forces unknown to the researcher or to the participants. Results may be incorrectly assumed to be fact, when in actuality they are influenced by previous assumptions. To demonstrate contextual awareness in this study, findings have been described, along with careful attention to the context from which they originated (Thorne, 2016).

**Probable truth.** Researchers seek to find truth in what is studied. However, Thorne (2016) cautions researchers to appreciate that what is believed to be truth might eventually be found to be false. Findings should rather be described as probable truth, realizing that they are the best representation of knowledge in the moment, and may be

disproven with new discovery (Thorne, 2016). The results of this study are presented with probable truth in mind, recognizing that although the results ring true for the present, they may not fully represent reality.

### **Ethics**

This research takes a community-based approach. Prior to developing research questions, Indigenous community members were consulted to learn about health priorities and affirm the relevance of the research. These consultations also helped to ensure the research was conducted in ways appropriate to local customs. See Appendix D: Consulted community organizations. The research was approved by the McMaster University Hamilton Integrated Research Ethics Board, Mohawk College Research Ethics Board and the McMaster University Family Medicine internal research review board. Funding support for the research was graciously provided by Canadian Institute of Health Research (CIHR) Fellowship—Priority announcement: Research in First Nations, Métis and/or Inuit Health.

### **Inclusion Criteria**

Indigenous mothers were invited to participate in the study if they fulfilled the following inclusion criteria: (a) self-identified Indigenous ancestry; (b) parenting an infant less than two years of age; and (c) living in Hamilton, Ontario. Health providers were included if they provided care to Indigenous mothers and infants in Hamilton, Ontario.

## **Consent**

Potential participants who contacted the researcher and met the study's inclusion criteria were provided with an information letter and consent form outlining: (a) the aims of the study, (b) its potential benefits and harms, (c) that participation is completely voluntary, (d) that participants can choose not to answer questions without penalty, and (e) that participants can choose to withdraw from the study at any time. Informed consent of the participants was sought for (a) their participation in an interview, (b) their participation in a discussion group, (c) the audio-recording of interviews and the discussion group to aid in transcription of the data, and (d) permission for the researcher to collect field notes throughout the research study to provide context to the transcript data. See Appendix E: Consent form.

## **Compensation**

Interviews took place in a location of convenience for the participant, and bus fare and/or parking costs to attend the discussion group were provided. Participants were given a small cash honorarium of twenty dollars to acknowledge their time to participate in the interview and lunch was provided at the discussion group.

## **Confidentiality**

All identifying data were stripped from transcripts to maintain participant confidentiality. Consent forms and all other hard-copies of data were kept in a locked cabinet in the locked office of the researcher's supervisor. Transcript data did not contain any identifying information and were stored electronically on a password-protected computer, in a locked office.

### **Tri-Council Policy Statement (TCPS)**

Special considerations were made to conduct research with Indigenous people in Hamilton, according to the Tri-Council Policy Statement in Chapter 9: Research involving the First Nations, Inuit and Métis Peoples of Canada. Details of how these guidelines have been considered and implemented are discussed in Appendix F: Application of the Tri Council Policy Statement 2, Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada.

### **Thesis Content**

This dissertation has been written as a sandwich thesis and is composed of six chapters, four of which have been formatted as journal articles, and have either been published (Chapter 2), or submitted (Chapters 3, 4 and 5). Chapter 2<sup>5</sup> is a published peer-reviewed manuscript that provides a formal and thorough review of the literature to date concerning how Indigenous mothers experience using health care services for their infants. The lack of literature concerning this phenomenon provided rationale to support conducting the primary study. The results from this primary study are presented in three additional manuscripts (Chapters 3-5); specifically, primary care, acute care and early childhood health promotion services respectively.

Chapter 3 consists of a manuscript entitled “Indigenous Mothers’ Experiences of Using Primary Care for their Infants.” The focus of this manuscript was to address how mothers access and use primary care services to meet the health needs of their infants

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<sup>5</sup> Selection and Use of Health Services for Infants’ needs by Indigenous Mothers in Canada: Integrative Literature Review (2018) *Canadian Journal of Nursing Research*, 50(2), 89-102.

using data from Indigenous mothers and primary care providers. Facilitators and barriers to the access and delivery of primary care for Indigenous mothers and infants is described, with an emphasis on the provision of four specific approaches to care (anticipatory, collaborative, culturally relevant and holistic). Findings show that the use of culturally safe, trauma and violence-informed and family-centered approaches to care can promote access and use of primary care by Indigenous mothers and infants.

In Chapter 4, “Mothers’ Perceptions and Experiences of Using Acute Care Health Services for Their Infants” provides a deeper conceptual understanding of the experiences of Indigenous mothers using acute care services to meet their infant’s health needs. Important factors that enabled access and use of acute services included children’s specialization, building trusting relationships and a holistic approach to care. Prolonged wait times, financial barriers and experiences of racism and discrimination resulted in negative experiences and in some cases prevented mothers seeking specialized pediatric care for their infants. Findings presented in this paper provided an opportunity to discuss the importance of providing culturally-safe and trauma and violence-informed health care in fast-paced acute care environments.

Chapter 5, entitled “How Indigenous Mothers Experience Selecting and Using Early Childhood Health Promotion Services to Care for Their Infants” describes the findings from Indigenous mothers and health providers as they relate to the use of early childhood health promotion services. While both mainstream and Indigenous-led programs use some similar strategies to support mothers caring for the health of their infants, this paper highlights how mothers experience Indigenous-led programs as most



effective. With the support of health policy and adequate government funding, health providers in mainstream programs can be enabled to better provide for the health of Indigenous infants and their families.

As Chapters 3-5 focus on separate aspects of the findings from the primary study, there is some amount of overlap of content. First the health of Indigenous people is described in each paper, as are the study design, methodology and methods. Both culturally safe and trauma and violence-informed care models are described in each chapter as findings indicate these are effective ways to care for Indigenous infants and their families in all health care contexts. References to other chapters are made by referring to manuscripts submitted for publication. Chapters also mention an integrative review of Two-Eyed Seeing that will be published in future and can be appreciated in Appendix B within this dissertation.

Finally, Chapter 6 summaries the findings of the entire study, and outlines contributions to and implications for health policy, nursing practice, education and future research.

All manuscripts (Chapters 2-5) are co-authored with the student, as first author. The first author contributed to the conception and design of the primary study and to the development and writing of each manuscript. Data analysis and interpretation were conducted with the first author and the research assistant, Rachel Bomberry. Each manuscript was written by the first author, with co-authors contributing to the depth and exploration of concepts and contributed to revisions.

## **CHAPTER TWO**

**TITLE:** Selection and Use of Health Services for Infants' Needs by Indigenous Mothers in Canada: Integrative Literature Review

**AUTHORS:** Wright, A., Wahoush, O., Ballantyne, M., Gabel, C., Jack, S.M.

**JOURNAL:** Canadian Journal of Nursing Research

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Selection and use of health services for infants' needs by Indigenous mothers in Canada: Integrative literature review. *Canadian Journal of Nursing Research*, 50(2), 89-102.

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### Abstract

In Canada, Indigenous infants experience significant health disparities when compared to non-Indigenous infants, including significantly higher rates of birth complications and infant mortality rates. The use of primary health care is one way to improve health outcomes; however, Indigenous children may use health services less often than non-Indigenous children. To improve health outcomes within this growing population, it is therefore essential to understand how caregivers, defined here as mothers, select and use health services in Canada. This integrative review is the first to critique and synthesize what is known of how Indigenous mothers in Canada experience selecting and using health services to meet the health needs of their infants. Themes identified suggest both Indigenous women and infants face significant challenges compared to non-Indigenous women and infants; colonialism has had, and continues to have, a detrimental impact on Indigenous mothering; and very little is known about how Indigenous mothers select and use health services to meet the health of their infants. This review revealed significant gaps in the literature and a need for future research. Suggestions are made for how health providers can better support Indigenous mothers and infants in their use of health services, based on what has been explored in the literature to date.

**KEYWORDS:** Canadian health services; infants; maternal/child; transcultural nursing; Indigenous people; equitable health access

In Canada, Indigenous infants experience significant health disparities when compared to non-Indigenous infants, including significantly higher rates of birth complications and infant mortality rates (10.2 to 23.1 versus 5 deaths per 1000 live births) (Smylie, Crengle, et al., 2010; Smylie, Fell, et al., 2010). Indigenous peoples, including First Nations, Métis and Inuit, are the fastest growing cultural group within Canada, with a population increase of 22% between 2006 to 2011 (Statistics Canada, 2013). It is therefore essential to understand the health needs of Indigenous infants to improve the health outcomes of this growing population.

Due to colonization, Indigenous people were forced to relocate to reserves, and lost their traditional governance structures, lifestyles and cultures (The Truth and Reconciliation Commission of Canada, 2012). Later, Indigenous children were removed from their homes to attend residential schools where they often experienced situations of neglect and abuse (The Truth and Reconciliation Commission of Canada, 2012). The impacts of these traumas have caused multigenerational effects on child development, self-worth, and health (Bombay et al., 2009; Hertzman, 2000; Lloyd et al., 2010; Nguyen, 2011).

Despite the potential benefits of living in urban areas, such as the availability of health services, adequate housing, employment and educational opportunities, the health of Indigenous infants born in urban areas remains similar to infants born on-reserve in rural areas that typically lack these amenities (Luo, Senécal, et al., 2010; Luo, Wilkins, Heaman, Smylie, et al., 2010; Martens et al., 2010; National Aboriginal Health Organization, 2009; Simonet, Wassimi, et al., 2010). This finding suggests that the one's

use of health services is not based solely on the availability of services, but other factors, including the social determinants of health, play important roles in enabling or inhibiting one's ability to select and use health services (Andersen, 1995).

The use of primary health care is one important way of improving health outcomes through preventative and health promoting measures (Guttmann, Shipman, Lam, Goodman, & Stukel, 2010; Kringos, Boerma, Hutchinson, van der Zee, & Groenewegen, 2010). However, studies suggest that Indigenous children in Canada under the age of six use health care services less often than non-Indigenous children (80% living off-reserve had seen physician in past year compared to 88% of all children in Canada, and 12% living off-reserve were unable to obtain health care compared to 0% of all children in Canada) (Smylie & Adomako, 2009).

### **Methods**

An integrative literature review using the Whittemore and Knafl (2005) approach, was undertaken to determine what is known of how Indigenous mothers, as caregivers, select and use health care services in Canada to meet the health needs of their infants. This five-staged approach includes: (a) problem identification, (b) literature search, (c) data evaluation of quality, (d) data analysis, and (e) presentation of data synthesis. The term 'infant' will be used to describe children less than two years of age. This age was selected to ensure mothers have had the opportunity for numerous interactions with the health care system.

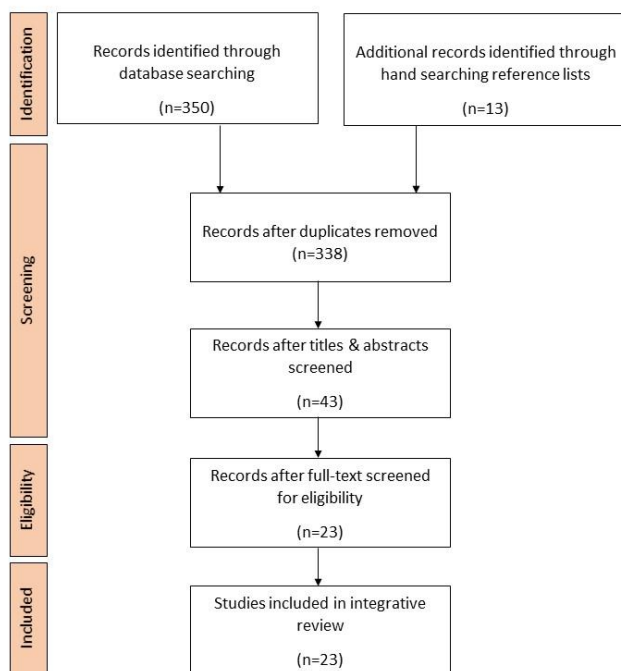
## **Search Strategy**

A comprehensive and systematic review of the literature was undertaken. Articles included in the review met the following inclusion criteria: (a) primary study conducted in Canada (b) focus on selection and use of health services by Indigenous mothers for their infants less than two years of age. Place of residence was not an exclusion factor.

Online databases (CINAHL, OVID Healthstar, EMBASE, AMED and Pubmed) were searched, using the search terms: Native OR Indigenous OR Métis OR Aboriginal OR Inuit OR First Nation\* OR Indian AND Infant OR baby OR toddler OR newborn AND health services AND Canad\*. Additional MeSH terms included: Indigenous population OR American Native continental ancestry group OR oceanic ancestry group. Only articles published within the last 20 years were considered for inclusion due to the ever-evolving health care landscape. Reference lists of relevant articles were then searched by hand. The use of further search terms significantly limited the results and did not lead to any new articles. Therefore, many articles were easily excluded by irrelevant titles and abstracts. Full articles were then read and further excluded if they did not meet inclusion criteria. Articles were excluded if they were not a primary study, if they included Indigenous people from countries other than Canada, if they did not pertain to the selection and use of health services, and if they did not include children less than 2 years of age. See Figure 1 for details.

Following article selection, data relating to health service selection and use were extracted, and an iterative thematic analysis was completed (Whittemore & Knafl, 2005). The analysis consisted of several phases. First, data were reduced by study design, and

each group was analyzed separately. Next, during data comparison, each piece of datum was systematically compared to every other piece of datum, using the constant comparison method suggested by Miles and Huberman (1994) and informed by Glaser (1978). Finally, similar data were grouped together to form the beginning of themes, which were then named as they were confirmed.



**Figure 1. Search Strategy**

## Results

A total of 19 primary studies were included in the review, including 4 cross-sectional studies, 2 cohort studies, 2 randomized controlled trials (RCT), and 11 qualitative studies. Articles were critically appraised and ranked for quality using the Critical Appraisal Skills Programme (CASP) checklist appropriate for their study methodology, to ensure the review was comprised of high quality literature, and to make

sense of the results . Of the studies included in the review, 12 were determined to be methodologically strong (met greater than 80% of criteria), 5 methodologically moderate (met 60 to 80% of criteria), and 2 were methodologically weak (met less than 60% of criteria). Regardless of methodologic quality, all studies were included for the review. See Table 1 for study details.

Resulting themes include: the health of Indigenous women, the health of Indigenous infants, the impact of colonialism on Indigenous mothering, use of health services, interventions to improve health service use, and how health providers can promote health service use.

### **Health of Indigenous Women**

Indigenous women face more disadvantage than both non-Indigenous women, and Indigenous men living in Canada (Smylie et al., 2011; Van Herk et al., 2011). Indigenous women experience higher levels of poverty, unemployment, inadequate housing, and poor nutrition and are at higher risk for diabetes, HIV, drug and alcohol addiction, Fetal Alcohol Spectrum Disorder (FASD), gestational diabetes and hypertension during pregnancy (Smylie et al., 2011; Tarlier et al., 2013; Van Herk et al., 2011). Indigenous women are younger than non-Indigenous women at the time of first pregnancy (9% of Indigenous children live with mothers less than 20 years of age compared to 1% of non-Indigenous children) (Smith et al., 2006). Indigenous women as compared to non-Indigenous women may seek prenatal care later, and or receive only limited or no prenatal care (Denison et al., 2013). Collectively, the increased health risks facing



Indigenous mothers not only result in poorer maternal health outcomes, but may also impact infant health outcomes.

### **Health of Indigenous Infants**

Approximately 20% of First Nations births are born large for gestational age (LGA), almost double the rate of non-Indigenous infants (Tarlier et al., 2013). Infants born with birth weights significantly higher or lower than what is considered healthy are at high risks for poor health outcomes that persist to adulthood. Infants born LGA are at high risk for developing type 2 diabetes later in life; are more likely to require intervention during delivery (labour induction, the use of forceps or vacuum for extraction, and caesarean sections), have an increased risk of birth injury; and experience high rates of postnatal death (Smith et al., 2006; Tarlier et al., 2013; Van Herk et al., 2011).

The rate of infants born small for gestational age (SGA) in a First Nations community was 5.7%, similar to the national average (Tarlier et al., 2013). Infants born SGA have an increased risk of poor growth, failure to thrive, and anemia, which translates to learning disabilities, school difficulties, behavioural and emotional health conditions, increased rates of morbidity, mortality, hypertension and diabetes later in life (Tarlier et al., 2013).

Infant mortality for Indigenous infants is more than two times that of non-Indigenous infants (Tarrant & Gregory, 2001), with higher incidences of otitis media, meningitis, FASD, mortality from Sudden Infant Death Syndrome (SIDS) and injury, and readmission to hospital shortly after birth than non-Indigenous infants (Johnson et al.,

2002; Smith et al., 2006; Van Herk et al., 2011). Additionally, higher rates of preterm birth have a significant impact on infant mortality for Indigenous infants (Tarlier et al., 2013).

Finally, immunization rates for Indigenous infants in Canada are less than national rates, though significant reporting difficulties exist. Only one study included in this review reported that just 5% of First Nations infants were adequately immunized at 6 months of age in a rural reserve community in a northern western province (Tarlier et al., 2013).

### **Impact of Colonialism on Indigenous Mothering**

Prior to colonization, many communities were matrilineal or egalitarian, with women holding influential roles in society (Van Herk et al., 2011). Following colonization, communities became largely patriarchal, as they became embedded in European culture (Van Herk et al., 2011). This change, coupled with residential schools, and the forcible removal of children from their parents, resulted in a loss of traditional ways of mothering, teaching and learning (Van Herk et al., 2011). Children in residential schools were separated for long periods, if not permanently, from their parents (Van Herk et al., 2011). Consequently, studies now show that many survivors of these schools have difficulty developing relationships with others, bonding with their children, and may not have effective parenting skills due to a lack of parental modeling as children (Van Herk et al., 2011).

The importance of mothering is recognized as having a protective effect on children's development and resiliency (Van Herk et al., 2011). The very act of mothering

holds immense healing potential for Indigenous communities (Van Herk et al., 2011). Pregnancy can be a life-altering event for many women, presenting an opportunity for change, and the motivation to improve one's situation for the sake of one's children (Smith, Edwards, Martens, & Varcoe, 2007; Smith et al., 2006). Ensuring that Indigenous mothers can select and use health services to meet their own health needs and the health needs of their infants is, therefore, essential to promoting health and a healing path from the effects of colonialism for the entire Indigenous community in Canada.

### **Use of Health Services**

Indigenous mothers describe a different experience in using health services when compared to non-Indigenous mothers. First, experiences of discrimination and racism when using health services negatively impacts the willingness of Indigenous mothers to seek future health care for themselves and their infants (Denison et al., 2013; Smith et al., 2006; Van Herk et al., 2011, 2012). Much of this is attributed to an overall lack of appreciation and understanding that health providers have for Indigenous history and the impact that colonialism has had and continues to have on Indigenous people (Smith et al., 2006; Van Herk et al., 2012). This lack of understanding has fostered the development of negative stereotypes that health providers then expect of their Indigenous patients (Van Herk et al., 2012). These inaccurate assumptions negatively impact health care provision which may cause mothers to delay seeking health care until a health crisis presents (Denison et al., 2013; Smith et al., 2006).

The threat of child-apprehension is a significant and real threat to Indigenous people (Denison et al., 2013; Gerlach, Browne, & Greenwood, 2017). A government-

legalized apprehension of children, termed the “Sixties Scoop”, occurred between 1960 and 1980, and resulted in the removal of thousands of children from their homes (Van Herk et al., 2011). Indigenous mothers who feel threatened by the risk of child apprehension, may avoid engaging with infant health programs, and/or may move to new and isolated locations to avoid this possibility (Denison et al., 2013; Gerlach et al., 2017). Indigenous children continue to be over-represented in the child welfare system in Canada (Gerlach, Browne, & Suto, 2016; Smylie et al., 2011) .

Living on reserve land in Canada complicates health service use by Indigenous mothers, as reserves are commonly rural, often remote, and the availability of health services is limited (Tarlier et al., 2013; Tarrant & Gregory, 2003). Communication with health providers has been cited as another barrier to understanding health information and treatment plans, subsequently leading to a lack of willingness to return for future care (Van Herk et al., 2012). Indigenous women have shared that they do not trust their health providers and worry their information will not be kept confidential (Gerlach et al., 2017).

Tarrant and Gregory (2001, 2003) cite inadequate health education as a cause of mistrust by Indigenous mothers whose children developed side effects after receiving vaccines in two northern First Nations communities. Mothers who were not adequately educated on expected side effects, became wary of vaccines they believed had harmed their children. Consequently, community Elders also became wary of vaccines, leading to a mistrust of health providers and vaccines in the communities. A study by Smylie, et al. (2011) found that Indigenous parents cited long wait lists, inability to arrange and afford transportation to services, unavailability of physicians and nurses, and inability to afford

services as barriers to health service use for their children. Finally, for Indigenous mothers experiencing severe disadvantage, priorities essential to survival, such as adequate housing and food security, may overshadow maintaining their health or the health of their children (Denison et al., 2013; Gerlach et al., 2016).

### **Interventions to Improve Health Service Use**

Intervention studies in Canada to improve the use of health services and health outcomes for Indigenous mothers and their infants report varying levels of success. In a Cree First Nations community in James Bay, evaluation of the effectiveness of maternal counseling during pregnancy on the incidence of childhood caries at 30 months of age found infants in the intervention group had fewer caries than the control group, although results were not statistically significant (R. Harrison, Veronneau, & Leroux, 2012). A study comparing the effect of maternal counselling versus both maternal counseling and fluoride varnish application in young children under the age of 5 years in Sioux Lookout, Ontario, showed that the latter intervention reduced the incidence of child caries at follow up (Lawrence et al., 2008). Another study demonstrated its unique prenatal care program for mothers with substance abuse issues in downtown Vancouver led to higher infant birth weight, fewer preterm births and a reduced incidence of infant withdrawal symptoms (Marshall, Charles, Hare, Ponzetti Jr., & Stokl, 2005). Two studies provided peer support to promote breastfeeding to community mothers (Banks, 2003; Martens, 1999). Both studies reported an increase in breastfeeding rates, and Martens (1999) reported improved satisfaction with breastfeeding and fewer problems. Aboriginal infant development program (AIDP) workers have successfully engaged parents in infant

programming, through a combination of home visits, and group programs (Gerlach et al., 2017, 2016). The program involved health workers who adapt programming to meet specific needs of families, using a relational approach. Workers stress the importance of understanding context, such as the influence of historical trauma on current health behaviours and outcomes, and emphasize that developing a trusting relationship with parents is essential to their participation in infant programming (Gerlach et al., 2017, 2016).

### **How Health Providers Can Promote Health Service Use**

Several suggestions to promote the use of health services by Indigenous mothers can be gleaned from this review. First, health providers should take a positive, strength-based approach when caring for Indigenous mothers (Smith et al., 2007, 2006). This approach includes acknowledging Indigenous mothers' identities as Indigenous women, as well as recognizing how historical experiences of colonialism continue to impact their lives today (Gerlach et al., 2016; Van Herk et al., 2011). This assists mothers in finding their voice, developing self-esteem and pride as mothers, and promotes a positive exchange with health providers, encouraging mothers to return for future interactions (Smith et al., 2007, 2006). Health providers should ensure their care is holistic, encourage mothers to embrace their culture and to incorporate these values into their care, and acknowledge and promote a mother's right to choose (Smith et al., 2006; Van Herk et al., 2011, 2012). Health providers should also ensure programming is tailored to the specific needs of the family (Gerlach et al., 2017). Indigenous mothers need safe places to receive health care, where they feel that they are not judged, where they are respected and

listened to, and where staff are welcoming. The presence of Indigenous health providers is described as promoting a sense of safety (Van Herk et al., 2011). Incorporating Indigenous Elders in infant health programs has been shown to promote parental engagement (Gerlach et al., 2017). These features are essential to promoting trusting relationships between health providers and Indigenous mothers (Smith et al., 2006; Van Herk et al., 2011; Wiebe & Young, 2011). Participants in one study, suggest that clinics engage the five senses; hearing, seeing, smelling, tasting and feeling; through art work and children's laughter and drumming, to promote culturally safe spaces for Indigenous mothers and children to receive care (Van Herk et al., 2012). Finally, health providers need to recognize that an Indigenous woman's identity as a mother is influenced by historical trauma, and that Western ways of mothering are not superior to Indigenous ways of mothering (Van Herk et al., 2011).

### **Methodological Concerns**

The reviewed literature is not without significant limitations. First, data from surveys relies on self-reported Indigenous ancestry (Johnson et al., 2002). For many reasons including stigma, participants may not report their ancestry, underestimating the results. Another study was limited by its reliance on a subjective assessment of infant well-being, which may cause inaccurate results (Marshall et al., 2005). In one RCT, an intervention may not have been effectively delivered due to provider time constraints (R. Harrison et al., 2012). In another RCT, too few details of its intervention are provided to determine the influence of confounding variables (Lawrence et al., 2008). A cohort study by Banks (2003) did not adequately describe their study methodology or participant

characteristics, compromising the validity of their results. While most qualitative studies were methodological strong, not all studies described a design methodology, recruitment of participants, rigorous data analysis, or how a relationship between the researcher and participant was accounted for. Despite these methodological concerns, findings are similarly presented across articles, suggesting there is a shared experience across Indigenous groups in Canada.

### **Discussion**

Indigenous mothers and infants face significant health disparities and barriers to selecting and using health care. Much of this stems from the implementation of the Indian Act in 1876, which disproportionately disadvantaged Indigenous women by its policies; Indian status designations were passed on to children only through Indigenous fathers, women were not allowed to participate in band government, and until 1985, Indigenous women who married non-status men lost their Indian status and its benefits, including the right to live on reserve land (Native Women's Association of Canada, 2007). This paternalistic hierarchy benefited Indigenous men, and perpetuated a belief of gender inequality (Barker, 2008). Additionally, policies such as the Indian Act and the residential school system have threatened the traditional role of mothering, and attempted to abolish Indigenous culture. Despite these tremendous barriers, Indigenous people remain resilient. Indigenous people are the fastest growing population in Canada and are working tirelessly to revitalize their culture and traditions, promote healing within their communities, and make changes to government and health policy.



Recognizing the unique health needs of Indigenous mothers and infants is imperative, and a sensitive approach to health care is vital. Health providers can best approach care of Indigenous mothers and infants by considering two unique frameworks; trauma and violence-informed care and culturally safe care. To provide trauma and violence-informed care, health providers must recognize and understand the impact that past and present trauma along with systemic and/or interpersonal violence have on an individual's circumstances (Varcoe, Wathen, Ford-Gilboe, Smye, & Browne, 2016). The principles of providing trauma and violence-informed care include recognizing how policies and procedures might inadvertently cause harm; providing care that is respectful, non-judgmental, and empowering; and the provision of safe and private spaces in which to have sensitive conversations and offer support (Catallo et al., 2013; Markoff, Fallot, Reed, Elliott, & Bjelajac, 2005; Varcoe et al., 2016). Similarly, the concept of culturally safe care has also been advocated for by Indigenous women as a way to promote healing for Indigenous people (Anderson et al., 2003; Canadian Indigenous Nurses Association [formally Aboriginal Nurses Association of Canada], Canadian Association of Schools of Nursing, & Canadian Nurses Association, 2009; Health Council of Canada, 2012; Smye & Browne, 2002). Nurses who provide culturally safe care have examined their own beliefs and their influence on interactions with other people. They strive to be open-minded towards people who are different from themselves, and to not blame victims of historical events for their current predicaments (Papps & Ramsden, 1996). In the process of considering cultural safety, health providers are reminded to reflect on how their practices might harm Indigenous people through reaffirming the effects of colonialism by

paternalistic practices and by disregarding historical trauma (Smye & Browne, 2002).

Applying these two frameworks to the provision of health care may assist health providers in meeting the needs of Indigenous women and their infants in selecting and using health care.

### **Areas for Future Research**

Studies to date have paid little attention to the experiences of Indigenous mothers selecting and using health services to care for the health of their infants. Studies have not described how mothers select health services for their infants. Studies conducted with First Nations communities on-reserve have explored only limited experiences of First Nations mothers caring for their infants, including oral health and obtaining immunizations. The contribution of data by Indigenous mothers is not specified in many studies, so it is unclear to what extent results reflect their unique perspectives.

Additionally, results are not specific to infants, as most participants are asked about parenting “young children,” the parameters of which were not defined or aggregated with data from parents with children older than two years. The urban experience of caring for the health of Indigenous infants remains poorly understood, with just 11 studies describing the experience of Indigenous mothers living in urban areas, and using health services to meet their infant’s health needs (Denison et al., 2013; Gerlach et al., 2017, 2016; Johnson et al., 2002; Marshall et al., 2005; Smith et al., 2007, 2006; Smylie et al., 2011; Van Herk et al., 2011, 2012; Wiebe & Young, 2011).

A realist review by Smylie et al. (2016) concluded that programs designed for Indigenous mothers and infants and/or toddlers by Indigenous communities, with local

goals in mind rather than those imposed by non-Indigenous outsiders, tend to produce positive results. Despite this, there remains a dearth of literature proving specific interventions that lead to improved health outcomes for Indigenous infants. Future researchers evaluating the effectiveness of interventions on Indigenous infant health outcomes should thoughtfully consider and incorporate these suggestions to promote success.

### **Conclusion**

In summary, the reviewed literature describing how Indigenous mothers select and use health services to meet the health needs of their infants is limited. Despite this, there are important recommendations for health professionals to improve how Indigenous mothers and infants select and use health care. These include gaining an understanding and appreciation for Indigenous history and the impact of colonization on health, building trusting relationships with Indigenous people, and considering trauma-and violence-informed and culturally safe approaches to care. Any interventions with Indigenous people should be done in collaboration with the Indigenous community, as only through this approach are the needs of Indigenous people truly realized and effectively met. Finally, this paper has demonstrated the need for future research to develop the foundational knowledge required to better support the health needs of Indigenous mothers and infants.

**Table 1: Study Characteristics**

	<b>Study design &amp; objective</b>	<b>Study setting</b>	<b>Data collection methods</b>	<b>Participant characteristics</b>	<b>Infant characteristics</b>	<b>Key findings related to health service selection &amp; use for infant's health</b>	<b>Study quality</b>
Banks (2003)	Cohort study Breastfeeding rates in First Nations women prior to and after intervention of support program	Kanesatake First Nation, Quebec	Incidence of breastfeeding and duration of breastfeeding measured over 6 years	Mothers discontinued breastfeeding prior to intervention starting for sore nipples, engorgement, inadequate milk supply, or to return to work or school.	Not described	Increased breastfeeding within first week by 43%, to 4 months of age by 23% Interventions should be community-led to be effective No statistical data provided	Weak
Cidro et al. (2014)	Qualitative study Infant feeding & oral health	Norway House Cree First Nation, Manitoba	Interviews and focus groups	31 Grandmothers & Great Grandmothers Ages 40-80, multiparous, Birthed children between 1930-1970 Describe their own children's feeding and oral health	Not described	Physician advice different than traditional advice Mothers as primary decision makers on infant feeding and oral health Preference for traditional medicine	Mod
Denison et al. (2013)	Qualitative study Child apprehension & experience of health service use	2 sites: Rural northern area & urban centre Western province	Semi-structured interviews	9 mothers with experience of child apprehension Ages 23-49 years 8 Healthcare providers	Not described	Threat of child apprehension did not impact women seeking care for their children Mothers experienced racism and discrimination in health care Negative experiences meant they did not seek care for themselves Trying to survive, therefore health care is not priority	Strong

	<b>Study design &amp; objective</b>	<b>Study setting</b>	<b>Data collection methods</b>	<b>Participant characteristics</b>	<b>Infant characteristics</b>	<b>Key findings related to health service selection &amp; use for infant's health</b>	<b>Study quality</b>
Gerlach et al. (2016)	Qualitative study Parental engagement in Aboriginal Infant Development Programs (AIDPs)	Urban, off-reserve, British Columbia	Qualitative interviews	10 Indigenous primary care givers 4 Indigenous Elders 18 AIDP workers 3 organizational leaders	<6 years	AIDP workers learned <i>from</i> not about communities to tailor programming to the needs and preferences of the community Importance of understanding role of trauma in current health circumstances AIDP workers had to assist parents with basic needs and their priorities before tackling child development and the program's agenda AIDP workers assist parents in gaining sense of belonging	Strong
Gerlach et al. (2017)	Qualitative study Parental engagement in Aboriginal Infant Development Programs (AIDPs)	Urban, off-reserve, British Columbia	Qualitative interviews	10 Indigenous primary care givers 4 Indigenous Elders 18 AIDP workers 3 organizational leaders	<6 years	Caregiver's experiences with child protection agencies influences willingness to engage in child programming AIDP workers had to work hard to gain caregivers' trust AIDP workers must be aware of and reflect often on their own privilege Incorporating Elders into programming promoted parental engagement AIDP workers must adapt programming to meet family's needs	Strong
Harrison et al. (2012)	Randomized control trial Incidence of child caries based on treatment (motivational interviewing)	Cree reserve communities at southern Hudson Bay, Quebec	272 Mothers (5 intervention and 4 control reserve communities) Blinded examiners Data related to dental caries, maternal dental knowledge, home-care behaviours and child quality of life	130 intervention, 137 control mothers Mean age intervention: 25.5 years, control 25.6 years	Not described	Intervention including education for mothers with motivational interviewing associated with decreased child severe dental disease Not statistically significant Absolute RR 11% (95% CI -3-30%) RR 0.86 (95% CI 0.66-1.07)	Strong

	<b>Study design &amp; objective</b>	<b>Study setting</b>	<b>Data collection methods</b>	<b>Participant characteristics</b>	<b>Infant characteristics</b>	<b>Key findings related to health service selection &amp; use for infant's health</b>	<b>Study quality</b>
Johnson et al. (2002)	Cross-sectional study Early maternal discharge and newborn readmission	Urban and rural, Alberta	CIHI Inpatient discharge database, Vital statics birth database, Health insurance plan registry file	81,956 deliveries 5,322 Indigenous births (6.5% of total sample)	2840 newborn readmissions, 332 (12% Indigenous) 90% term gestation 84% delivered at home region	86% newborn readmissions within 6 days of life Jaundice most common reason for readmission Indigenous infants had significantly higher rates of newborn readmission (odds ratio 2.15, CI 1.8-2.5), reasons unknown	Mod
Lawrence et al. (2008)	Randomized control trial Impact of caregiver counselling (control) versus fluoride and caregiver counseling (intervention) on incidence of child caries	20 First Nations communities in the Sioux Lookout Zone, Northwest Ontario	Pre and post intervention data over 2 year follow up.	150 non-Indigenous children in control group from Thunderbay, 1275 children from reserve communities, 380 allocated to control, 915 allocated to intervention	Children <5 years, 63% of participants <2 years of age 47.6% males in control group, 50.1% males in intervention group, 52% males in Thunder bay group	18.3% reduction in child caries in intervention group, not statistically significant (Adjusted odds ratio 1.95, 95% CI 1.07-3.57) Caregiver counselling may improve health behaviours and reduce caries in high risk First Nations children	Strong
Marshall et al. (2005)	Cross-sectional study How maternal services are associated with infants' well-being	Urban, single access women's health centre, Vancouver, British Columbia	Retrospective chart review	1,152 women Ages 14-55 80.7% Indigenous	Infant mortality of population 7.25 per 1,000 live births (higher than 4.68, provincial rate at the time)	Sheway maintain prenatal contact with clients Infant withdrawal symptoms decreased (approx. 40% to 18%) Preterm birth rate declined (41% to 20%) Low birth weight rate declined (23% to 15%) Longer prenatal care at Sheway associated with higher birth weight	Mod

	<b>Study design &amp; objective</b>	<b>Study setting</b>	<b>Data collection methods</b>	<b>Participant characteristics</b>	<b>Infant characteristics</b>	<b>Key findings related to health service selection &amp; use for infant's health</b>	<b>Study quality</b>
Martens (1999)	Cohort study Evaluation of support program interventions to improve satisfaction and duration of breastfeeding	2 hospitals servicing members of Sagkeeng First Nation, Manitoba. One acting as control and one as intervention	Mixed design using pre/post surveys, and semi-structured interviews and chart audits to add context to quantitative findings	41 mothers in intervention arm, 34 mothers in control arm. 63.4% of intervention arm initiated breastfeeding, 69.7% control arm initiated breastfeeding.	Not described	The maternal support programs resulted in increased initiation (38% to 60%, Odds Ratio 2.2, 95% CI 1.2-4.1, P=0.01), decreased early weaning RR 0.47 (95% CI 0.22-0.99, p=0.04), increased satisfaction with breastfeeding and decreased number of breastfeeding problems.	Strong
Smith et al. (2006)	Qualitative study Safe & responsive care experience of health service use	Urban & rural Aboriginal health centres British Columbia	Interviews and small group discussions	57 Community leaders, health providers and community members 61.4% Indigenous Unclear number of Indigenous mothers	Not described	Pregnancy an opportunity for healing Safe & responsive care resulting in earlier antenatal care, planned pregnancies, healthy choices during pregnancy, interest in parenting training, increased breastfeeding	Strong
Smith et al. (2007)	Qualitative study Safe & responsive care experience of health service use	Urban & rural Aboriginal health centres British Columbia	Interviews and small group discussions	73 key informants, leaders, health providers and community members 60.3% Indigenous Unclear number of Indigenous mothers	Not described	Respond to pregnancy and parenting as opportunity to create better future for children Safe and responsive care improves relationships between Indigenous mothers and health providers, and facilitates healing Experiences of unsafe care previously prevented mothers from seeking care	Strong

	<b>Study design &amp; objective</b>	<b>Study setting</b>	<b>Data collection methods</b>	<b>Participant characteristics</b>	<b>Infant characteristics</b>	<b>Key findings related to health service selection &amp; use for infant's health</b>	<b>Study quality</b>
Smylie et al. (2011)	Cross-sectional study Develop baseline population health database for urban Indigenous people in Ontario	Urban, Hamilton & Ottawa, Ontario sites	Survey	60% men, 40% women 64% participants have children 20% participants finished high school 18% completed some or all of college, and 5% some or all of university 69.2% received provincial/municipal social assistance/welfare	Not described	22% of parents have concerns about child's development 56% of parents have concerns about child's health Long wait lists for children to receive care Reported poor/fair health in 5.3% of children ages 0-5 years 55% children not participated in community health promotion programs .	Strong
Tarlier et al. (2013)	Cross-sectional study Prenatal and infant primary care in remote First Nations communities	On-reserve, remote northern community Western province	Retrospective chart review	65 mothers Ages 14-39	63 infants, 50% male	Inadequacy of current health care system in providing primary care for Indigenous infants in remote communities Nurses must have knowledge and skills required.	Strong
Tarrant & Gregory (2001)	Qualitative study Mother's perceptions of child vaccinations	On-reserve, 2 rural First Nations communities in Sioux Lookout, Ontario	Semi-structured interviews	28 mothers, ages 18-41 years Have 1-8 children	7 participants had children <5 years of age appropriately immunized	Fear of disease promoted vaccine use Not convinced vaccines are effective or safe Immunizations are traumatic Time constraints, wait times and illness when immunization was available were barriers to uptake	Weak
Tarrant & Gregory (2003)	Qualitative study Mother's perceptions of child vaccinations	On-reserve, 2 rural First Nations communities in Sioux Lookout, Ontario	Semi-structured interviews	28 mothers, ages 18-41 years Have 1-8 children	7 participants had children <5 years of age appropriately immunized	Knowledge barriers, negative stories from others, and Elder's opinions of immunizations led to mistrust of health care system, health providers and led to decreased child immunization uptake	Strong



	<b>Study design &amp; objective</b>	<b>Study setting</b>	<b>Data collection methods</b>	<b>Participant characteristics</b>	<b>Infant characteristics</b>	<b>Key findings related to health service selection &amp; use for infant's health</b>	<b>Study quality</b>
Van Herk et al. (2011)	Qualitative study Health providers perceptions of Indigenous mothers and their use of health services	2 Urban Aboriginal health centres Province unknown	Semi-structured interviews	21 leaders, health providers and family members 62% of participants Indigenous Unclear number of Indigenous mothers	Not described	How Indigenous mothers are perceived by health providers influences the care they receive	Mod
Van Herk et al. (2012)	Qualitative study How space/place influences care Indigenous mothers receive	Urban area, 2 Aboriginal health centres and 2 mainstream health centres Province unknown	Semi-structured interviews	39 leaders, health providers and clients. 67% of participants Indigenous	Not described	Providing safe spaces and places improves how Indigenous mothers access and use health services, essential to provision of good and quality health care, promotes healing, sense of community Incorporating traditional cultural traditions into care is best for Indigenous people's health	Mod
Wiebe & Young (2011)	Qualitative study Parent views of culturally congruent care in NICU	Urban, Edmonton Alberta NICU	Qualitative interviews	21 families 6 Indigenous	8 females, 18 males Gestational age 24-38 weeks	A non-trusting relationship with staff resulted in parents being more vigilant in being at their infant's bedside, and less forgiving for misunderstandings Health providers taking time to answer questions, teach parents reduced parental stress Indigenous parents expressed importance of traditional healing practices with their infant	Strong

Note. Due to space limitations, the following short-forms have been made: In many cases, only first authors have been cited, Mod=moderate, %=percentage, CI=confidence interval, RR=relative risk, <=less than

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### **CHAPTER THREE**

TITLE: Indigenous Mothers' Experiences of Using Primary Care for their Infants

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### Abstract

**Purpose:** Access to primary care can help mitigate the negative impacts of social inequity that disproportionately affect Indigenous people in Canada. Despite this, however, Indigenous people cite difficulties accessing care. This study seeks to understand how Indigenous mothers— typically responsible for the health of their infants— living in urban areas, experience selecting and using health services to meet the health needs of their infants. Results provide strategies to improve access to care, which may lead to improved health outcomes for Indigenous infants and their families.

**Methods:** This qualitative interpretive description study is guided by the Two-Eyed Seeing framework. Interviews were conducted with 19 Indigenous mothers and 5 primary care providers.

**Results:** The experiences of Indigenous mothers using primary care for their infants resulted in eight themes. Themes were organized according to three domains of primary care: structural, organizational and personnel.

**Conclusions:** Primary care providers can develop contextual-awareness to better recognize and respond to the health and well-being of Indigenous families. Applying culturally safe, trauma and violence-informed and family centred approaches to care can promote equitable access and positive health care interactions which may lead to improved health outcomes for Indigenous infants and their families.



The use of health services is an important way to promote health and well-being. Despite this, however, many Indigenous people in Canada experience inequitable access to health care, citing barriers such as racism, a fear of judgement and a lack of traditional Indigenous health services (The Truth and Reconciliation Commission of Canada, 2015). Primary care is one of several types of health services available in Canada, and refers to the community-based comprehensive provision of health promotion, treatment and management of non-emergency and chronic health conditions across the lifespan (Canadian Nurses Association, 2015). While the use of primary care is important at every life stage, primary care has important implications for infants, as it is associated with reduced infant mortality (Brandon et al., 2016). Indigenous infants in Canada experience poorer health outcomes and higher rates of infant mortality than non-Indigenous infants, and yet how they access and use health services remains largely unknown (Smylie, Fell, Ohlsson, & Joint Working Group on First Nations, Indian, Inuit and Métis Infant Mortality of the Canadian Perinatal Surveillance System, 2010; Wright, Wahoush, Ballantyne, Gabel, & Jack, 2018).

This article reports part of a broader study that explored how Indigenous mothers living off-reserve in a city experience the phenomenon of selecting and using health care services to meet the health needs of their infants, and included 31 participants. Participants included 19 mothers, five primary care providers (PCPs) and seven providers of early childhood health promotion services<sup>6</sup>. The results presented in this article reflect

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<sup>6</sup> Early childhood health promotion services consist of parenting supports that promote parent-infant attachment and healthy infant growth and development.

the data as they relate specifically to the experiences of selecting and using primary care. The objective of this research is to help inform primary care delivery and health policy, which may lead to more equitable access to primary care for Indigenous mothers and infants.

### **Background**

The social determinants of health such as income, education, gender and access to health care, play a key role in the health of individuals (C. Reading & Wien, 2009). In addition, racist and discriminatory policies stemming from the impact of colonization mean that Indigenous people in Canada are particularly susceptible to poor health outcomes resulting from social inequities (Browne et al., 2012; The Truth and Reconciliation Commission of Canada, 2015). Adequate access to primary care is one important way to mediate the effects of inequities that result in higher rates of disease, injury and mortality for some Indigenous infants (C. Reading & Wien, 2009; Jeff Reading & Halseth, 2013; Smylie et al., 2010). Yet despite these potential benefits, 13% of mothers in Canada report difficulty accessing care for their infants (Brandon et al., 2016). An earlier study with First Nations parents in Hamilton, Ontario, reported barriers that included long wait lists, transportation problems and an inability to afford health services (Smylie et al., 2011).

Mothers are most commonly responsible for making health-related decisions for their children (Minkovitz et al., 2005), and, thus, understanding their experiences of how they select and use health care for their infants is imperative for providing care that better meets the health needs of their infants. Research with Indigenous mothers in Canada's

urban areas is particularly important, as a recent census showed that 56% of Indigenous people live in urban areas, and that more than half of these are women (Government of Canada, 2014; Statistics Canada, 2018).

### **Methods**

This qualitative research study was guided by methodological principles of interpretive description (ID) as developed by Thorne (2016), and the application of the Two-Eyed Seeing approach to ensure the inclusion of both non-Indigenous and Indigenous worldviews (Bartlett, et al., 2012). The study was philosophically grounded in constructivism and naturalistic inquiry and underwent review and approval by three ethics bodies: the Hamilton Integrated Research Ethics Board, Mohawk College Research Ethics Board, and the McMaster University Family Medicine program.

Founded in nursing epistemology and disciplinary goals, ID emphasizes development of usable knowledge that offers practical application for clinicians (Thorne, 2016). Two-Eyed Seeing stresses the importance of viewing the world through both Western (mainstream) and Indigenous worldviews (Bartlett et al., 2012). The application of Two-Eyed Seeing to this study has resulted in a community-engaged approach to research, in which the question and subsequent study development was informed by the Indigenous community, as well as a Métis Scholar who sits on the researcher's Supervisory Committee, and a First Nations nurse who worked alongside the researcher through the entire research process. Further details of how Two-Eyed Seeing was applied will be available in a future publication.

### **Reflection of the Researcher**

When using ID – and congruent with Indigenous approaches to research – it is recommended that the researcher reflect on their beliefs, values and motivation for the study (Lavallée, 2009). Briefly, the first author is a non-Indigenous nurse practitioner of European settler ancestry. She acknowledges that her upbringing has been dominated by mainstream Western culture, and that as such, she benefits from unearned privilege. She seeks to engage in ethical interactions between members of Indigenous and Western cultures in Canada. Her nursing perspective values an understanding of the lived experience of others, to promote health and well-being and to provide individualized nursing care (Thorne, 2016). As a nurse researcher, she seeks to co-create knowledge through understanding the experience of others, valuing similarities and differences, and collaboratively creating wisdom that will benefit all (Bartlett, Marshall, & Marshall, 2012).

### **Setting and Sampling Techniques**

This study took place in the city of Hamilton, Ontario, located on the traditional territory of the Haudenosaunee (Ontario Federation of Labour & Ontario Federation of Labour Aboriginal Circle, 2017), and close to two reserves including Six Nations of the Grand River and Mississaugas of the New Credit. Indigenous people make up 1.7% of the Hamilton population, and Indigenous children aged 14 and younger represent 2.8% of all children (Statistics Canada, 2015a). The majority of First Nations residents report living below the poverty line, and face high rates of diabetes, hepatitis C, hypertension and mental health concerns (Smylie et al., 2011). Although most First Nations children (83%)

are said to have been seen by a PCP in the past year, many First Nation parents state concerns about their child's physical and mental/emotional well-being, and nearly 5% with children younger than five, view their children's health as only fair or poor (Smylie et al., 2011).

The experiences of Indigenous mothers and PCPs informed our understanding of this phenomenon. A purposeful sample of Indigenous mothers who met the following inclusion criteria were invited to participate: (a) self-identified Indigenous ancestry; (b) parenting an infant less than two years of age; and (c) living in Hamilton, Ontario. Snowball sampling was used, by asking participants to provide names of contacts with similar experiences. Within the study, theoretical sampling informed decisions to explore aspects of the phenomenon arising from interactions with participants that would require further depth (Patton, 2015).

The initial goal was to recruit a sample of 30 mothers, or to recruit until data redundancy was realized, and the emerging themes demonstrated information power - that is, the ability of the data to provide a comprehensive understanding of the phenomenon under study (Malterud, Siersma, & Guassora, 2015). Recruitment procedures consisted of poster invites, flyers, and word of mouth by the researcher, research assistant and Indigenous service providers at the Indigenous Friendship centre (IFC) in the city. To develop a deeper understanding of the contextual factors influencing the phenomenon, we sought to triangulate our data by also including PCPs in the study. A purposeful sample of providers who worked in primary and early childhood services with Indigenous mothers and infants in Hamilton were invited to participate. Health providers

were recruited via email and phone invitations, and by word of mouth. The expected number of health providers to be recruited was 10.

### **Data Collection**

Data were collected using semi-structured, one-on-one interviews with mothers and PCPs. Data were also collected from mothers in a discussion group, and interviews were facilitated by ecomaps. These strategies were used to honour the oral tradition which is important to Indigenous people (A. Wright, Wahoush, Ballantyne, Gabel, & Jack, 2016). All mothers completed a single interview, lasting approximately one hour, at a location convenient for the participants. This was most often in their home, or at the IFC. The questions were designed using Andersen's *Behavioral Model and Access to Medical Care* (1995), which was developed to help researchers understand the variables associated with equitable access to health care. The model suggests that environmental factors, characteristics of the population, health behavior and health outcomes work together to influence how an individual interacts with, and uses, health services (Andersen, 1995).

The interviews with mothers were augmented by ecomaps, which originated from systems theory and ecology, and have been used by social workers and nurses in clinical practice to visually depict family supports and resources (Hartman, 1995; Stewart & Allan, 2013). When used as a method of data collection in research, it is a collaborative way to engage participants in conversation about which services they access or use, and to help them identify the nature or quality of support received from that service (Rempel, Neufeld, & Kushner, 2007; Stewart & Allan, 2013). Sitting side by side when making the ecomap was helpful in limiting power inequalities between the researcher and mother.

The use of ecomaps helped to keep the interview focused, as they provided a visual reminder of what had and had not been discussed.

Interviews with PCPs took place with the researcher at a location convenient for the PCP, most often in an office or over the phone, and lasted approximately one hour. All PCPs completed a single interview. The questions were developed to elicit additional contextual details about the themes emerging from the mothers' data.

Finally, once all data were collected, and the initial analysis complete, a discussion group was held with the mothers to provide an opportunity for member checking and to further expand on and clarify any concepts that had emerged. Member checking is not required in ID (Thorne, 2016) but was essential to validate the researcher's interpretations of the mothers' experiences in the absence of Indigenous lived experience. All 19 mothers were invited to attend and eight joined. The discussion lasted approximately 90 minutes and was facilitated by the researcher, while the research assistant recorded observations that later added context to the transcript. Mothers were asked to confirm themes emerging from the data and were given an opportunity to clarify or remove data they felt was misunderstood. They did not ask for any data to be removed. Further clarification was sought regarding their self-identifying as Indigenous to health providers, as well as how their infant's physical, mental, emotional and spiritual health needs were expressed and how they could be met by health providers.

All interviews and the group discussions were audio-recorded for transcription and analysis using NVIVO 12 (QSR International, 2018). Field notes provided insight into interactions between the researcher and the participants, the research setting, details

relating to context, and the influence of the physical environment on participants (Mulhall, 2003). All data were stored in the researcher's locked office.

### **Data Analysis**

A thematic data analysis was undertaken, guided by Thorne (2016), Two-Eyed Seeing (Bartlett, Marshall, & Marshall, 2007) and by consulting the ecomaps. Data analysis in ID is not merely a description of the data, but rather an interpretation of the patterns found within them, and the relationships and interactions between the patterns (Thorne, 2016). The final product of an ID study is a thematic summary. It does not strive to claim the production of new concepts, but rather to present the phenomenon in a new way that furthers clinicians' understandings of the phenomenon, relationships between its elements, and new and meaningful ways to apply the knowledge to their clinical work (Thorne, 2016). Through the application of Two-Eyed Seeing, data analysis was initially completed independently by both the researcher and the research assistant. Both then came together to compare results over the period of many months and to clarify each other's interpretations of the data, so that consensus could be reached on the presence of codes and eventual themes. The research assistant provided valuable insight into local customs, traditions and contexts that were at play. In this way, Two-Eyed Seeing was used to promote the interweaving of Western and Indigenous ways of knowing.

The analysis began during data collection and continued through the final, more formal analytic phases (Thorne, 2016). Only broad-based and generic coding strategies were applied until the researcher and research assistant were fully engrossed in the data and understood the relationships between various elements within the phenomenon. The



analysis was conducted in several stages. First, transcripts were read multiple times to see possible patterns within the raw data. Data were placed into broad categories that were not narrowly defined or limiting. This process of pattern recognition progressed into a further examination of the relationships and possible meanings between the patterns (Thorne, 2016). NVIVO was used to organize the ongoing development of codes, their definitions, criteria for when and when not to use the code, along with quotations illustrating the code from transcripts (MacQueen, McLellan, Kay, & Milstein, 1998). Data from the PCPs were analyzed to provide additional context to emerging themes in the mothers' data. Finally, the ecomaps were used as a visual confirmation of the analysed transcripts, including information about which services were used by whom, and which met specific health needs (physical, emotional, mental and/or spiritual).

Data analysis progressed through four conceptual stages as described by Morse (1994); comprehending, synthesizing, theorizing and recontextualizing. In the first phase, the researcher learned all they could about the setting or participant experiences (Morse, 1994). This process continued throughout the data collection, with formal analysis helping to deepen the understanding of the phenomenon as a multitude of new questions arose. The second phase was synthesizing. Early concepts and codes evolve into patterns, and differences between these patterns were explored and explained (Morse, 1994). Common characteristics were discovered, revised and verified. In the theorizing phase, explanations of the patterns were developed, requiring the researcher to ask additional questions and consider other theoretical or empirical sources for explanation (Morse, 1994). When the researcher was satisfied with the depth of the data, the fourth and final

recontextualizing phase began; data were synthesized into a form applicable to a wide range of contexts (Morse, 1994). At this point, it was important that practical application of the findings and elements of the phenomenon were depicted in a way that was memorable and practical for clinicians to use in their practice. Keeping these four phases in mind while analyzing the data allowed the researcher to conceptualize moving from an exploration of the data to presenting them in an organized thematic summary (Thorne, 2016).

Themes were organized using three discrete domains of primary care as described by Hogg et. al (2008): structural, organizational and personnel. The structural domain is comprised of system-level elements that influence care delivery, including policies, funding and governance and community-level policies, population characteristics and infrastructure (Hogg et al., 2008). The organizational domain refers to policies and factors that influence the provision of care, while the personnel domain refers to factors relating specifically to PCPs and how they provided care (Hogg et al., 2008).

## **Results**

The findings in this article represent the experiences of 24 individuals; 19 mothers and five PCPs (family physicians/nurse practitioners). An additional seven providers of early childhood health promotion services were also interviewed, and their data will be presented in a future publication. Of the participant mothers, 15 identified as First Nations, two identified as Métis, and two were unsure of their specific Indigenous culture. The median age of the mothers was 28 years and approximately one-third were first-time mothers. All but one infant had a regular PCP. See Table 1: Demographic information:

Participant mothers. One PCP identified as First Nations, and all other PCPs were non-Indigenous.

Results from the triangulation of interviews, ecomaps and the discussion group are presented in three stages below. Descriptions by the participant mothers of how they selected PCPs are articulated, followed by the circumstances in which they used PCPs and finally their experiences of using primary care to meet the health needs of their infants.

### **PCPs Are Selected Based on Convenience**

When asked how they select primary care services to meet the health needs of their infants - including the provision of vaccinations or treating illnesses - mothers described selecting a PCP based on convenience. Mothers were an existing patient of the PCP they chose to care for their infant, or if they did not have a PCP, they sought a new one based on recommendations from a family member or friend. In the absence of these recommendations, mothers chose a new PCP simply because the primary care provider was accepting patients and available. As one mother explained, “I found him in the phonebook. At the time he was a new doctor and he was looking for patients. My sister and a couple of people I knew go to the [clinic] down there, so I figured why not?”. No mothers in this study described investigating a PCP for quality, acceptability, or their ability to meet their infant’s health needs prior to becoming a patient.

### **How Mothers Use Primary Health Services to Meet Their Infant’s Health Needs**

When asked how they use their PCP to meet their infant’s health needs, mothers described using their PCP for: (a) *routine care*; (b) *health education*; and (c) *non-*

*emergent treatment*. All mothers described using their PCPs to access routine infant care, including vaccines, assessment of appropriate growth and development, and well-baby check-ups. The provision of newborn health education by PCPs was inconsistent, with some mothers receiving this, while others did not. Those who did not receive education from their PCP sought information elsewhere (the internet, public health services or other early childhood health promotion services). Experienced mothers wanted their infant's PCP to initiate health education, regardless of their parenting experience, because they had received this education many years previously. One mother expressed her need for a reminder of basic health information for her newborn: "I haven't had a baby in four years and I was back to square one. I was nervous...". In contrast to the reported experiences of these mothers, the PCPs interviewed in this study shared that they routinely provided health education to all mothers.

Mothers used their infant's PCP for routine health services as well as for meeting any non-emergent health needs. These included a visit to their infant's PCP for a fever, cold, ear or eye infections, breathing issues and skin disorders. Mothers preferred to see their infant's PCP for these non-emergent issues rather than seek care at emergency departments (EDs), however they would attend the ED if they were dissatisfied with the PCP's care, or if they were unable to get an appointment.

### **Experiences of Using Primary Health Services**

Eight themes relating to how mothers experienced using primary care for their infants were organized according to the three domains of primary care. Further sub-themes were created as appropriate. A summary of all these elements can be found in

Table 2: Thematic summary. The following describes each of these themes in more detail, using the voice of participants.

**Structural.** Mothers described two themes within the structural domain, including: (a) *neighbourhood influences health*; and (b) *multi-service clinics*.

***Neighbourhood influences health.*** Mothers described how Hamilton's economically-deprived neighbourhoods in which they lived were characterized by high rates of crime and that living there was detrimental to their health. They were unable to comfortably leave their homes with their infants after dusk for fear of violence from members of the community, which limited their ability to exercise and be outdoors. They suggested that living in these neighbourhoods negatively influenced their infant's PCP such that PCPs demonstrated feelings of apathy towards the community by running "ghetto" and unwelcoming clinics. One mother described her experience of attending a run-down clinic in her neighbourhood:

...you have to expect living in this area you're not going to get the best healthcare... It seems like they care less when you're in a poverty-stricken area...the doctor's office is kind of ghetto looking. They just threw it together it kind of seems... It doesn't feel personable, it doesn't feel welcoming, it doesn't feel warm, and it feels like you're in and out, and they are not doing their job. They don't ask you how you're doing, as they would in a different nicer area. Ya, I guess in the area you live in you can expect different treatment.

Conversely, mothers who had attended clinics in more affluent neighbourhoods were overwhelmed by spacious clinics that were well-maintained and visually appealing but made them feel out of place.

...It was so nice! Like this is going to sound ghetto. Like a high-class pediatrician because they were giving out free baby Tylenol. Right? And my pediatrician doesn't do that for me... a lot of parents when I looked around, you can't help but notice, but they were older, lighter skin parents...They like were more classier

looking type of people...I felt a little uncomfortable when we were waiting in there.

Mothers equated the attention and care put into providing a welcoming and clean clinic environment as a reflection of a PCP's care for their patients. Thus, the participants perceived that delivering services in the dirty and run-down clinics in their neighbourhood meant that PCPs did not care about them.

***Multi-service clinic.*** Several mothers expressed that the availability of numerous services within the same facility would improve their experience. Two mothers had accessed primary care clinics that provided a nutritionist, pediatrician and other health providers within the same building as their PCP. Their perceptions of care at these facilities were that they offered better access to specialty services than relying on referrals from their PCPs to other services in the community. Another mother described the ideal primary health service as one that combined early childhood health promotion services with access to PCPs.

**Organizational.** Mothers described four organizational policies that influenced their experiences of using primary care for their infants, including: (a) *flexible appointments*; (b) *alternative options for care*; (c) *welcoming receptionists*; and (d) *welcoming spaces*.

***Flexible appointments.*** Mothers stressed the need for flexibility in scheduling appointments and for being respected when they changed or cancelled appointments. Many mothers had several children and were balancing busy and complex lives that occasionally required appointments to be re-booked. Additionally, many mothers did not want to take public transit with a sick infant and were at risk for cancelling appointments

if their ride became unavailable. Several clinics penalized those who cancelled appointments by charging fees or threatening to de-roster patients. For mothers already struggling financially, these consequences were devastating. One mother described her experience, including when an office staff threatened to file a report to child protection services if she continued to cancel:

They were kind of like very... pushy about appointments? Like I was also very small when I had her [my daughter], and I was losing weight for some reason and very sick. So they wanted me in every two weeks. But the one appointment they scheduled me for was December 27<sup>th</sup> ... I had Christmas dinner that day, so I called to reschedule it... They are like, "You can't miss this appointment. If it happens again we are going to have to call [child protection services]" ... they were just really rude about it. It kind of sucked. That was like one of the starters in me switching appointments or like switching doctors.

Primary care providers were aware that some patients had competing priorities that influenced their ability to attend appointments and endeavored to provide flexibility. Often these families were known to the clinic and as a result, they capitalized on any visit the mothers could make, whether by appointment or as a walk-in, getting as much done as possible, such as blood work and physical examinations, amongst others. One family physician working at a primary clinic for women living in the downtown core shared:

I think all of the clinicians understand that those populations really need to, when they call in or they show up, you see them. Because that is a moment that they're coming and asking for assistance. They probably had a moment to come and see you then. If you don't capitalize on that you might not be able to see them for a month or so.

Mothers also wished PCPs could see their infant on the same day they called seeking an appointment. They expressed worry about their inability to detect their infant's subtle signs of illness, so they needed a professional's opinion. Mothers who were worried

about the health of their infants said they would not wait for a later appointment but would rather go to an alternative walk-in clinic or ED to have their child seen right away.

Health providers understood that an infant's well-being was a source of anxiety for mothers and that they often wanted access to service the same day they called. They did their best to see infants in that situation, but organizational policies and scheduling restrictions made this difficult. In some cases there were no options other than to send mothers and infants to after-hours alternatives.

*Alternative options for care.* When their PCPs were unavailable, families were sent to seek help elsewhere. Many mothers sought care at their neighbourhood walk-in clinics or the ED. Mothers reported that some clinics provided care after-hours into the evening, while others provided on-call triaging services where a physician or nurse practitioner could speak with a mother to determine if care was needed urgently. Some mothers were penalized for seeking care at walk-in clinics; they were charged fines or were threatened with the removal of their infant from the PCP's roster. A mother shared her dilemma of using a walk-in clinic:

My doctor's office, they tell you specifically do not go to walk-in clinics because you will be billed for it because they have their own walk-in clinic. Which a lot of patients aren't happy with because it is only from five-thirty to seven at night, and you're lucky if you get to see someone because it is so packed.

Despite these consequences, mothers sought care when required. This most often meant going to an ED where they would not be financially penalized by their PCP.

*Welcoming receptionists.* Receptionists were often the point of first-contact and their interaction with families set the tone and perception of the clinic. Positive interactions occurred when the receptionists were welcoming, familiar and friendly, and



took care to remember infant's names. Negative experiences included instances when receptionists were rude or unfriendly, threatened to involve child protection services for cancelling or rescheduling appointments, or when they breached confidentiality. The threat of a report to child protection services was particularly damaging for mothers, who felt shamed, judged and angry after these encounters. Mothers who experienced these threats were uncomfortable returning for care; they felt their parenting was under surveillance and their ability to maintain custody of their children was at risk. Mothers who overheard receptionists speaking with colleagues about a patient's personal health information felt they too were at risk for having their information shared inappropriately. This experience made mothers wary of sharing personal information for fear others in the waiting room would hear. One mother shared an example of her experience overhearing the inappropriate remarks of a receptionist:

... a patient had called for a refill of painkillers and she [receptionist] got off the phone and started talking to the other receptionist in front of everybody [about] what the girl just called about. And she is like, "Oh yes, she called this many times for [percocet], and I told her she is not getting them." ... they said her name, the girl's name, and got off the phone... the whole waiting room could hear what they were talking about. So, I wouldn't appreciate that if somebody was talking like that about my business.

Positive interactions with receptionists were associated with good experiences of using the clinic, while the opposite was true of negative encounters. In some cases, negative interactions resulted in mothers not returning for care; they found another PCP or used alternatives like a walk-in clinic.

*Welcoming spaces.* Mothers expressed the need for welcoming spaces for individuals seeking care, including comfortable waiting rooms, reasonable wait times and

an accepting atmosphere for individuals of different cultural backgrounds. Small waiting areas felt crowded to mothers, who found it difficult to keep young children seated while they waited to be seen. Mothers felt small and dirty waiting rooms caused further harm to their infants, as they increased their risks of contracting illnesses from other patients. Long wait times were problematic, as infants who felt unwell were often fussing or crying, bothering others and making mothers feel self-conscious. Mothers suggested PCPs could mitigate these challenges by providing age-appropriate activities in waiting rooms, such as TVs, books, or toys. One mother explained:

Yes, and my doctor is a very thorough man. He likes to explain everything, which is great, and I can see why the backlog happens, because he is like that. But when you have a 6-month old that's coming in for his first needles and you have to wait an hour and half, and I have held off breastfeeding because I wanted to give it to him once the needles come and he is upset. That is super frustrating.

Mothers also expected clinic to be welcoming to people of all cultures. Some of the mothers felt judged by others for their Indigenous heritage and wanted their children to feel welcomed by PCPs. One mother shared:

I feel like if everyone was welcomed no matter what kind of race you were, or color, where you came from I feel like that would be ideal. I feel like it shouldn't be secluded for just one race or culture. I feel like that is where we go wrong sometimes.

Some suggested creating a dedicated clinic space for displaying art work and languages of different cultures; however not representing Indigenous cultures while incorporating many other cultures was interpreted as racist, and left mothers feeling devalued by PCPs.

**Personnel.** Many characteristics of the PCP enabled or inhibited a positive experience or access to care. These characteristics are grouped in two themes: 1) *Relationships are key* and 2) *Approaches to care*.

***Relationships are key.*** Mothers repeatedly emphasized the importance of having a relationship with their infant’s PCP. The building blocks of developing these relationships were woven throughout mothers’ stories of their experiences with primary care, as relationships were important not only for them, but equally important for their children. Relationships are key is represented in four sub-themes, including: (a) *building trust*; (b) *consistent provider*; (c) *communication skills*; and (d) *gender of PCP*, while a fifth sub-theme, (e) *discriminatory care*, is detrimental to building relationships.

***Building trust.*** Mothers needed to trust their infant’s PCP to feel they were receiving appropriate care and to experience a reciprocal and non-threatening relationship. Mothers who believed they were being seen by a nurse and not a nurse practitioner or physician, felt that their infant’s health concerns were disregarded, leading to feelings of mistrust. Many mothers were unable to recognize whether they had been seen by a nurse or nurse practitioner at their primary care clinic because the health provider was referred to as “nurse” (i.e. Nurse Betty). Other mothers were unaware that nurse practitioners provided similar care to family physicians. Misdiagnoses, lack of professionalism and breaches in confidentiality also weakened or damaged the sense of trust for mothers. This then led to negative experiences and to seeking care in other places like the ED. One mother explained how her negative experiences with her infant’s pediatrician influenced her to prefer obtaining care at the ED:

Interviewer: Do you typically call your pediatrician first and then go the hospital?

Participant: I used to, like when my I had my oldest, I use to call. But I think at least two years after dealing with her, I just stopped calling.

Interviewer: So now you just go to [the ED]?

Participant: The hospital... [or the] walk-in clinic.

Health providers also recognized the importance of building a trusting relationship with patients. They acknowledged how trust created a comfortable environment allowing mothers to feel open to share their health concerns. One family physician described the importance of trust in her interactions with mothers and infants:

...when they sort of trust what you're saying and even if they're uncomfortable, they know they will be going home with a plan of action. And it is like okay, I am nervous because my child is sick or I am nervous about this or whatever, but I have a good enough relationship with my doctor to know they're not concerned so I should not be concerned.

Trust also improved adherence to treatment, as mothers understood the reasons for it and had confidence in their health provider's ability to manage their health.

*Consistent provider.* Mothers described that seeing the same consistent PCP for their infant assisted in building relationships establishing trust. Mothers whose infants saw different care providers at each visit reported that PCPs were often not up to date on their infant's condition or clinical course. One mother shared:

...to me [it's] just a hassle when you go see a different person every time. They don't know what to begin with, where to start or they don't know what has already been wrong with her, or if anything has been wrong with her. And to me I would rather follow up with someone who knows you already, they know what has already happened to her, what she already got and you know. And it is easier to diagnose when you know a person.

Gaps in information or understanding meant mothers had to explain their infant's health history at every visit, causing frustration and wasted time.

*Communication skills.* A PCP's ability to effectively communicate with mothers and their infants was another important component of building relationships and promoting positive interactions. Communication skills experienced as helpful included taking the time to listen and acknowledge concerns, which made mothers feel they were

heard and that their concerns were taken seriously. It also meant valuing mothers as experts of their own children and validating their insight. Mothers who expressed that their PCP communicated well also perceived that their PCP cared about their infant's well-being. Mothers who felt they were not listened to were less likely to trust their PCP's opinions and suggestions. One mother describes her experience of a PCP's ineffective communication skills:

No, she just does not listen. I bring them in. She looks at him, [and says] "Oh he is fine" and sends him out. Like I brought him there, he had a bad ear infection. She just sent him away so I went to a walk-in clinic. And his ear infection was inflamed... Well if she actually took the time and looked at my kid and listened to what he is saying... She does her own thing and walks out.

Mothers who experienced ineffective communication were more likely to seek an opinion at another care facility for their infant, like a walk-in clinic or ED.

*Gender of PCP.* Seven participants shared that they felt more comfortable with a female PCP, especially during more intimate exams associated with pregnancy and postpartum. Mothers spoke of their inherent trust of women, who they perceived as generally more emotional and caring. They related this to their own histories of violence with men, and their desire for their children to grow to respect women. One mother described how a child who grows up surrounded by women is given the best chance to learn to respect them, and to be cared for and nurtured emotionally.

I feel like a baby his age, especially when there has been so much violence against women. I have been a victim of it... I feel like if you are in an environment full of women you learn to respect women. I don't want him to grow up and be disrespectful. I want him to grow up and appreciate the women around him... I feel like if we had access to a doctor's office... with all female staff that would be ideal in my opinion.

*Discriminatory care.* Some mothers described traumatic experiences of unethical care related to racism and discrimination. Mothers who experienced racism and discrimination in their interactions with PCPs attributed this to assumptions based on their Indigenous appearance and/or last name (some names were common amongst Indigenous people in the area). One mother described how she believed her children's appearance and last name led to their higher risk of experiencing racism:

When you look at my babies you know they are Native American. When you look at my older ones, oh my goodness they got freckles. They are cute and they just look like little Caucasian babies right? But my younger ones, they don't...it's very hard for me to wrap my head around how somebody could treat me the way they did because of who, not even who I am...but just because of my race. I think I am crying too because I am scared. I am scared for them. There isn't a day that doesn't go by when I think about things that they have to go through just because of who they are.

Other mothers felt discriminated against for having children at a young age. They perceived that their PCP believed they were unfit to parent because they were young mothers. One participant described being coerced into undergoing a breast exam by a male physician and student despite voicing her discomfort. She was told she could not revoke her consent to allow learners to participate in her care, and that the clinic would not provide her with a female health provider for this intimate exam. She left feeling traumatized and refused to seek medical care for years after this event. Yet another mother described how her age prevented her from giving informed consent:

...they wouldn't give me an option for certain things. Like the needles. They wouldn't explain to me what the needles were before they gave them... They just kind of brought me to the appointments and gave the kids needles. Not even my consent or anything... I am like, "What if there is a certain kind that I don't want them to have, or they don't necessarily need?" ...they just didn't give me those options...I know they would have given [options] to older parents.

Another mother shared how being a young mother led to discriminatory care: “I am assuming they thought that because I was nineteen, I didn’t know what I was doing. So the typical, people thinking that young moms are bad moms. Which is silly.” Both mothers attributed this discriminatory care to their young age, and believed older mothers received more respectful and informed care.

***Approaches to Care.*** Equally important to building relationships was how a PCP approached their provision of primary care. *Approaches to care* relates to how mothers expect health providers to deliver care to their infants and other family members and are described in four sub-themes, including: (a) *anticipatory guidance*; (b) *collaborative care*; (c) *culturally relevant care*; and (d) *holistic care*. Each is uniquely important to the experiences voiced by participants and presented individually.

*Anticipatory guidance.* This refers to the ability of a PCP to predict which knowledge and skills mothers needed to care for their infant (Hsu, Lee, Lai, Tsai, & Chiu, 2018). Mothers whose PCPs counselled them on what to expect also said they were more confident in their understanding of their infant’s health, needs and treatment plans. Those who had seemingly not been provided anticipatory guidance felt insecure in their knowledge of their infant’s health, and worried about what came next in terms of monitoring and treating health issues. The provision of basic infant health education as noted above was also an important form of anticipatory guidance. It prepared mothers for upcoming developmental milestones and how to care for common illnesses. One mother explained that she would rather her infant’s PCP share “...this is what is happening, this is what we are going to do, this is what is going to happen at the next appointment”.

Health providers recognized the need for anticipatory guidance. They also explained that this type of care was time-consuming, requiring them to book longer appointments with infants and mothers to ensure sufficient time to spend with families.

*Collaborative care.* Mothers expressed the importance of an engaging PCP who took a collaborative approach. Collaboration meant allowing mothers to hold their infants during uncomfortable and/or painful exams and procedures, as well as involving them in decisions about their infant's health. Mothers felt their values and beliefs were supported when they engaged in decision-making with their infant's PCP. A collaborative approach to care contributed to building trusting relationships, leading to positive interactions.

*Culturally relevant care.* Mothers strongly believed that their infant's PCPs should provide culturally relevant care. They felt this could be accomplished by having an understanding and appreciation of Indigenous history, and by valuing and supporting cultural and spiritual beliefs as they relate to health and well-being. Mothers recognized the inability of most PCPs to incorporate traditional Indigenous medicine into their treatment plans but expected PCPs to respect its place in health and healing, and to provide links to cultural resources in the city. An excerpt from the discussion group describes how mothers believed an understanding of how culture and associated trauma from colonization influences negative stereotypes of Indigenous people:

Participant mother 1: It bothers me just overall how uneducated the health care system... Like I said, we are the original people, you should know so much about our history and it should be so incorporated.

Participant mother 2: ...I still meet people every day that know nothing about it. I am like really? There is a reason for that drunken person on the bench.

Participant mother 1: I know. And it's true then they look at them and think ugh, drunk Indian.

Participant mother 2: Or they think they're lazy.



Participant mother 3: If you have to legally take your WHMIS [workplace health and safety program] to work then why shouldn't you be able to take something that makes you culturally sensitive?

Primary care providers shared conflicting stories of their ability to provide culturally relevant care. Some providers had taken cultural training in their workplace, while others recognized their need for cultural training to understand of the impacts of colonization and better familiarize themselves of the city's culturally-based resources for Indigenous people. One nurse practitioner shared their insight into providing culturally relevant care:

I am also realizing that I have been very privileged in my life. So I try to keep myself very centered and aware of that. Like when it seems a very easy way to solve a problem [it] isn't, and it's because of the multiple traumas in their life...I think what I try to do is I try to create a safe space and I try to listen more than I actually talk. And I make sure when I do talk that I make it very clear that my expertise are more Western philosophies and thoughts. That there is much more than that. Like traditional medicines and smudging, and just being with our Elders... It doesn't matter if I think they need to quit smoking, it's whatever they need and what they want to do.

The provision of culturally relevant care is important to mothers because they encounter negative stereotypes about Indigenous people in their interactions with their infant's PCPs. This subsequently leads to negative encounters and affects their decisions to return for care.

*Holistic care.* Mothers were asked to reflect on the physical, emotional, mental/developmental and spiritual health needs of their infants. Mothers described physical needs as vaccinations, treating illness and disease, promoting a healthy body and nutritional education. Emotional health needs were defined as comforting the infant, fostering feelings of safety, and providing love and attention. Mental/ developmental

needs included progressive development in cognitive, motor, language and play skills. Finally, spiritual health needs included praying with or for the infant, participating in traditional ceremonies, developing an Indigenous identity and traditional medicine.

Mothers generally felt their PCPs were meeting their infant's physical health needs. Approximately one-third of participants with a family physician and two-thirds of participants with a midwife (2 of 3 participants) perceived that their PCP met their infant's emotional and mental/developmental health needs. Only one participant of the entire group, however, believed their PCP (family physician) could meet their infant's spiritual health needs; this PCP worked at the Aboriginal health centre.

While all mothers believed their infants had physical, emotional and mental/developmental health needs in infancy, fewer felt they had spiritual health needs (79%). Those who thought their infant was too young to have spiritual health needs believed that they would develop these as they grew older. Some mothers felt their infant's spiritual needs were met by family members, and it was not necessary for their PCP to meet these needs. Others felt their infant's PCP should incorporate traditional medicine into care, or otherwise link them with traditional and cultural resources in the city.

The PCPs in this study were proud of their abilities to provide holistic care, including emotional, mental and physical health needs. However, most felt ill-equipped to care for the spiritual needs of Indigenous infants, as they lacked awareness of available cultural resources in the city. Those who were confident in caring for the spiritual needs of Indigenous infants had received specific cultural sensitivity training by their

employers. Each of the PCPs recognized this area for growth and expressed a desire and willingness to learn how to better meet the spiritual needs of their Indigenous patients.

### **Discussion**

This is the first qualitative study to ask Indigenous mothers living in a Canadian urban centre how they select and use health services to care for the health needs of their infants and provides a vital understanding of what is needed to improve access and use of primary care services. Results speak to the challenges experienced by mothers, which may be mitigated by taking an approach to primary care that intersects culturally-safe, trauma and violence-informed (TVIC), and family-centred care (FCC) models (Figure 1).

Mothers described their desire for PCPs to be sensitive to the needs of Indigenous people and to understand how historical events and current trauma impact health behaviour, use of health services and health outcomes. The literature suggests a culturally-safe approach to care is an effective way to accomplish these goals (Browne et al., 2016; The Truth and Reconciliation Commission of Canada, 2015). Culturally-safe care was initially described by Maori nurses in New Zealand who believed it imperative that health professionals understood not only the differences between their own beliefs and values and those of their patients, but also recognized the unintended potential to cause harm to patients as a result of their ignorance (Papps & Ramsden, 1996). What is considered culturally-safe can only be determined by those receiving care; however, health professionals can adjust their care provision to move from an awareness of cultural differences to an understanding of how their actions can impact another's access and health care experience (Papps & Ramsden, 1996). The urgent need for culturally-safe

health care practices has been recognized in the *Calls to Action* by the Truth and Reconciliation Commission of Canada (TRC), where health professionals are instructed to educate themselves on the history of colonization in Canada and its continued impact of resulting historical trauma on the health of Indigenous people today (The Truth and Reconciliation Commission of Canada, 2015). Once health professionals have an accurate understanding and appreciation of the history of Indigenous people in Canada, they can adjust their care accordingly, abolish negative stereotypes, achieve equitable access to health care, and improve health outcomes.

Primary care providers who provide TVIC are aware of potential harm and trauma impacting the lives of Indigenous families and mitigate this potential through applying TVIC principles to their care. For example, mothers in this study shared experiences similar to findings reported by other research; of discrimination, relating to their age as young mothers, and racism and discrimination, that negatively impacted their ability to access health care for their infants (Ballantyne, Benzies, Rosenbaum, & Lodha, 2015; Martens et al., 2012). Indigenous mothers tend to be younger than non-Indigenous mothers; more than a quarter of First Nations children living off-reserve having mothers ages 15 to 24 years compared to just 8% of non-Indigenous children (Smylie & Adomako, 2009). Teenage pregnancy has been found to be detrimental to a woman's health, as it increases her vulnerability to poverty, single parenthood and depression, and lowers her chances of obtaining a high school diploma, and subsequent employment (National Collaborating Centre for Aboriginal Health, 2012). Applying TVIC principles to the care of young mothers, PCPs can provide safe places for intimate exams and

sensitive conversations, avoiding perpetuating further trauma and harm (Varcoe et al., 2016). In this same way, PCPs can better appreciate how trauma and social inequities may impact a mother's ability to parent.

Involvement of child protection services is especially traumatic for Indigenous families due to historical trauma from the residential school system and Sixties Scoop in which children were forcibly removed from families, and the over-representation of Indigenous children in the care of child protection services (The Truth and Reconciliation Commission of Canada, 2015). Threatening to involve child protection services as a punitive action for missed appointments has the potential, therefore, to be extremely harmful to families, and result in mothers not returning for care, potentially putting the health of mothers and their infants at risk (Denison et al., 2013). Indeed, the mothers in this study shared their feelings of shame, anger and mistrust of their infant's PCPs when these instances occurred.

Using TVIC principles, PCPs can take a strengths-based approach with Indigenous mothers and infants, build trusting relationships and involve social and community supports that can help to counter the presence of risk factors (Varcoe et al., 2016). Clinics can promote confidentiality, and ensure sensitive conversations take place in safe and private areas (Varcoe et al., 2016). Organizations can provide a welcoming space, with receptionists who are also trained in culturally-safe and TVIC (Varcoe et al., 2016).

Racist and discriminatory policies in health care represent another form of structural violence that result in trauma for many Indigenous mothers and infants. This

trauma can be intergenerational, passed down through generations, and has been demonstrated to negatively impact mental and physical health (Varcoe et al., 2016). Mothers in this study who did not experience racism or discrimination may have been cared for by contextually-aware health providers, or otherwise protected by policies that make identifying Indigenous people living off-reserve difficult. People are not obligated to disclose their Indigenous identity in Canada, and many choose not to for fear of receiving racialized treatment.

Inequities are a continuing reminder of colonization and its impact on Indigenous people, as evidenced by the social context of the mothers in this study: lower income and education, adolescent pregnancy, and involvement of child protection services. Indeed, the neighbourhoods in which mothers and infants lived were an example of structural violence; as people living in neighbourhoods with lower socio-economic status have a higher likelihood of exposure to pollutants, noise, and inadequate housing which negatively impact child development and overall health and well-being (Conroy, Sandel, & Zuckerman, 2010; Hertzman, 2010). Financial penalties for mothers who take their infants to walk-in clinics is another example of how social inequity and resulting poverty negatively impact access to health care, and how further harm is caused by policies and practices that discriminate against those experiencing poverty.

Applying culturally-safe and TVIC principles, a PCP can care for Indigenous mothers and infants in ways that can help to mitigate inequity, as well as improve access to primary care. The mothers stressed anticipatory guidance as one important approach to promote positive interactions and relationships with their infant's PCP. Single mothers

with low socio-economic status and low levels of education are at high risk for stress, anxiety and depression, and a PCP can apply this kind of guidance to help reduce distress, at the same time enabling mothers to make informed choices to promote their child's health and development (Hsu et al., 2018). Mothers who are well-informed and know what to expect for the care of their infant (ie. follow up visits, developmental milestones, safety precautions) are more confident parents (Hsu et al., 2018).

Mothers desired that their PCPs address their infant's cultural and spiritual needs, as well as provide holistic care. They wished for Indigenous traditional ceremonies and medicines to be respected. Supporting the cultural and spiritual needs of children, especially in urban areas, has been demonstrated as important to their development of self-esteem and confidence (Gerlach, Browne, & Suto, 2018; Priest, Mackean, Davis, Briggs, & Waters, 2012). Mothers suggested that PCPs who were comfortable meeting the cultural and spiritual needs of their patients might incorporate traditional medicine into their practice. However, they also recognized that PCPs were largely unaware of cultural resources in the community – a factor also recognized by PCPs themselves. Indeed, health services that work in “silos” or independent from one another, avoiding collaboration and information sharing, contribute to families and health providers being unaware of their existence (Moore, McDonald, Carlon, & O'Rourke, 2015). Health providers who are uncomfortable addressing spiritual well-being can acknowledge spiritual health needs as valid and legitimate, take time to inquire about the spiritual well-being of their patients, and link those who are interested with appropriate resources in their neighbourhoods.

Finally, a FCC approach to primary care is an important way to engage the family unit and improve access to care. Initially described in the 1950s, FCC advocates for the bringing together of families through the recognition of a child's family as the primary caregivers and constant within a child's life (Harrison, 2010)(T. Harrison, 2010)(T. Harrison, 2010)(T. Harrison, 2010)(T. Harrison, 2010)(T. Harrison, 2010). A FCC approach should influence all levels of health care from health policy to practice, integrating the family into decision-making and care provision for their child, and recognizing the diversity of families and their need for holistic care (Harrison, 2010). While most health providers believe FCC is inherently good for children and families, they remain unclear on how best to implement FCC principles, particularly those related to culturally-safe care (Dennis, Baxter, Ploeg, & Blatz, 2017; Shields, 2015). The results of this study suggest PCPs can provide FCC for Indigenous infants and families by recognizing the family in every aspect of care and by being holistic in their approach (Shields, 2015).

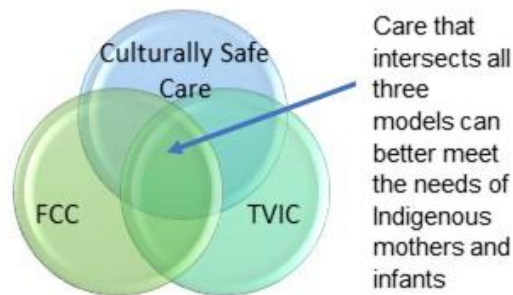
Perhaps most importantly, and as advocated for by mothers, FCC requires a relationship that is built on trust, enabled through continuity of care, and maintained without judgment, racism or discrimination. In an integrative review of trust between a patient and PCP, Murray & McCrone (2015) suggested its presence can increase a patient's participation in their care, their use of primary care services and their satisfaction with these services. Mothers described several ways that PCPs can build trusting relationships, also demonstrated in the literature: effective communication skills - that is, listening, understanding patient experiences and context – as well as displaying empathy and spending the necessary time with patients to adequately address their



concerns (Murray & McCrone, 2015). A FCC perspective emphasizes a collaborative approach to the care of infants, an additional avenue to the establishment of trusting relationships. This enables a PCP to work in a family's best interest and knowing infants are truly cared for, helps mothers impacted by social inequity and structural violence to feel safe in the healthcare environment. Ensuring infants are seen by the same PCP at each healthcare encounter also contributes to building trusting relationships, and has been found to reduce emergency hospital admissions (Huntley et al., 2014; Murray & McCrone, 2015). Ensuring mothers are aware their infants are being cared for by a nurse practitioner who can diagnose and treat their infant's health concerns is also key. A friendly and welcoming environment that minimizes power imbalances between PCP and mothers is important to an FCC approach to care, building trust and promoting equitable access to care (Murray & McCrone, 2015; Varcoe et al., 2016).

Primary care that integrates culturally-safe, TVIC and FCC models is an effective way of improving access to care and promoting positive interactions between PCPs and Indigenous mothers and infants. A culturally-safe lens provides PCPs with an understanding of how culture impacts health and well-being, while a TVIC lens can help health providers appreciate the implications of structural violence with its resulting trauma and inequity. While a TVIC approach includes culturally-safe care principles, primary care for Indigenous people requires that PCPs have a thorough understanding of the role of culture in health and well-being as well as the importance of the provision of holistic care. Used in combination, these three approaches can help to balance social

inequities, improve access to primary care and improve health outcomes for Indigenous infants and families.



*Figure 1.* The intersection of culturally-safe, TVIC and FCC models

### **Limitations**

There are several limitations to this study. First, this study largely reflects the experiences of First Nations mothers living in an urban area off-reserve, and not all mothers were strongly connected to their culture. Their experiences, therefore, do not reflect those of Inuit mothers, and may not reflect those of Métis mothers, or mothers with a strong sense of Indigenous identity. Next, Indigenous fathers or other parenting partners were not interviewed in this study, and they offer perspectives that are useful in the provision of primary care for Indigenous infants. Finally, the health providers who took part in this study likely did so because they believed they provided acceptable or exemplary care. Their experiences, therefore, may not reflect those of all health providers caring for Indigenous patients, and may not reflect the experiences of all Indigenous mothers seeking care for their infants, and mostly likely represent the best case.

## **Conclusions**

This study is the first qualitative study in an urban centre in Canada to ask Indigenous mothers how they select and use primary care to meet the health needs of their infants. The experiences of Indigenous mothers reflect the importance of intersecting three models of care; culturally-safe care, TVIC and FCC. Through the TRC and its mandated Calls to Action, health providers are encouraged to engage in education to enhance their awareness of how colonization has resulted in social inequities, structural violence and trauma for Indigenous people.

This research resulted in a remarkable, though perhaps not surprising, finding. The suggestions made by Indigenous mothers on how best to improve interactions with health providers – and consequently also improve health care access for their infants and families - are generally within the power of the individual. PCPs can therefore directly implement these insights to the way they provide care, rather than wait for changes to health policy, funding bodies, management. or other structural constraints that are less mutable and take time. These changes offer the potential of a meaningful and positive impact on the health and well-being of Indigenous infants during their early development, a period when access to primary care is critical to health outcomes over the life span.

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Table 1

*Demographic Information: Participant Mothers*

<b>Variable</b>	<b>Category</b>	<b>Frequency (%)</b>
Age	<25 years	5 (26)
	26-30 years	8 (42)
	>31 years	6 (32)
Number of Children	First time moms	5 (26)
	2-5 children	14 (74)
Education	Less than High school	9 (47)
	Completed only high school	3 (16)
	Some College/University	7 (37)
Marital Status	Single/Separated	9 (47)
	Married/Common-law	10 (53)
Indigenous Identity	First Nations	15 (78)
	Métis	2 (11)
	Inuit	0 (0)
	Unknown Indigenous heritage	2 (11)
Income	Full-time Employment	7 (37)
	Ontario Works (social assistance)	10 (53)
	Disability Pension	2 (10)
Change of address during life of infant	Moved at least once	10 (53)
	Same residence	9 (47)
Regular Health Care Provider	Family physician	17 (90)
	Pediatrician	1 (5)
	None	1 (5)

*Note: N=19*

Table 2

*Thematic Summary*

<b>Domain</b>	<b>Theme</b>	<b>Sub-theme</b>
<b>Structural</b>	Neighbourhood influences health	
	Multi-service clinic	
<b>Organizational</b>	Flexible appointments	
	Alternative options for care	
	Welcoming receptionists	
	Welcoming spaces	
<b>Personnel</b>	Relationships are key	Building trust
		Consistent provider
		Communication skills
		Gender of PCP
		Discriminatory care
	Approaches to care	Anticipatory guidance
		Collaborative care
		Culturally relevant care
		Holistic care

## **CHAPTER FOUR**

**TITLE:** Indigenous mothers' Perceptions and Experiences of Using Acute Care Health Services for Their Infants

**AUTHORS:** Wright, A., Jack, S.M., Ballantyne, M., Gabel, C., Wahoush, O.

Submitted to Qualitative Health Research journal and formatted to the specific requirements of the journal. It is currently under review.

### Abstract

**Background:** Access to acute care services is important to minimize morbidity and mortality from urgent health issues, however Indigenous people describe difficulties accessing care. An understanding of how Indigenous mothers experience selecting and using health services for their infants may assist in improving acute care service access and delivery and ultimately lead to improved outcomes for Indigenous infants and their families.

**Methods:** This qualitative interpretive description study included data from interviews and a discussion group with 19 Indigenous mothers. Data analysis was collaborative and informed by Two Eyed Seeing.

**Results:** A thematic summary resulted in six themes: (a) problematic wait times; (b) acute care is costly; (c) children's specialty; (d) trusting relationships; (e) racism and discrimination; and (f) holistic care.

**Conclusions:** This study offers practical ways for health providers to provide culturally-safe and trauma and violence-informed care for Indigenous mothers and infants in an acute care context.

Access to health services for urgent health conditions is vital for minimizing morbidity and mortality, yet despite this, many Indigenous people in Canada commonly encounter difficulties accessing health services. Indigenous infants experience higher rates of mortality and admission to hospital than non-Indigenous infants, and therefore their effective access and use of acute care services (ACS) is an important way to improve health outcomes (Heaman et al., 2010; Luo et al., 2010; Smith et al., 2006; Smylie et al., 2010).

Acute care services aim to efficiently diagnose and treat urgent health conditions, and in Canada include emergency departments (ED), urgent care centres and specialized hospital care (Ontario, 2016). Community walk-in clinics also commonly treat urgent health conditions, while telehealth services frequently act as a first step to determining whether ACS are necessary (Canadian Institute for Health Information, 2018). All types are referred to here as ACS.

The literature of how Indigenous infants access ACS is limited, particularly in urban settings. Most studies to date use aggregate data representing children of all ages, focusing on First Nations people who live on-reserve (typically in rural areas) and limiting health service use to oral health and immunization rates (A. Wright et al., 2018). The literature suggests that First Nations infants experience higher rates of accidents requiring ACS compared to non-Indigenous infants (Browne, McDonald, & Elliott, 2009). Hospitalization rates were also greater for First Nations and Inuit infants in the first year of life than non-First Nations or Inuit infants in a cross-sectional study in Quebec, Canada (unadjusted risk ratio (uRR) 2.05, 95% confidence interval (CI) 1.99-2.11 and uRR 1.37,

95% CI 1.24-1.52 respectively) (He et al., 2017). Finally, in a study from a large city in Ontario, First Nations people were noted to use the ED twice as often as non-Indigenous people (52% vs. 22%) (Smylie et al., 2011).

Since mothers typically decide when and how to seek care for their children, understanding their experiences using health services for their infants may provide important information on how best to promote equitable access and positive health care experiences for them. To address this knowledge gap, this study began by asking the following research question: How do Indigenous mothers living off-reserve in urban areas experience selecting and using health services to meet the health needs of their infants? The broader study included 31 participants; 19 mothers, five primary care providers and seven providers of early childhood health promotion services<sup>7</sup>. The results presented here relate specifically to how the mothers experienced using ACS for their infants. The findings will help to promote equitable access and positive experiences when Indigenous mothers and infants use ACS which may lead to improved health outcomes.

This study was conducted in the city of Hamilton in the province of Ontario, which sits on the traditional territory of the Haudenosaunee and is located adjacent to the Six Nations of the Grand River and Mississaugas of the New Credit reserves (Ontario Federation of Labour & Ontario Federation of Labour Aboriginal Circle, 2017). Indigenous people represent 1.7% of the total population, and Indigenous children under the age of 14 years make up 2.8% of all children (Statistics Canada, 2015a). A study in Hamilton revealed that First Nations parents in the city reported higher rates of asthma,

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<sup>7</sup> Early childhood health promotion services consist of programming supporting healthy parent-infant attachment and the growth and development of infants.

allergies, and chronic ear infections in their children when compared to non-First Nations children; and five percent of parents rated their children's health as only fair or poor (Smylie et al., 2011). Hamilton is an important place to explore the phenomenon of how Indigenous mothers select and use ACS for their infants, as research results can potentially impact many Indigenous infants and families.

### **Methods**

This qualitative Interpretive Description (ID) study (Thorne, 2016) is guided by two conceptual frameworks: Two-Eyed Seeing (Bartlett, Marshall, & Marshall, 2012) and Andersen's *Behavioral Model and Access to Medical Care* (Andersen, 1995). Three ethics boards reviewed and approved the study, including: the Hamilton Integrated Research Ethics Board, Mohawk College, and the McMaster University Family Medicine program. A thorough description of the methodology has been published elsewhere (Wright, Jack, Ballantyne, Gabel, & Wahoush, Submitted October 15, 2018 to the International Journal of Qualitative Studies on Health and Well-being) and can be consulted for further detail.

Interpretive Description stems from nursing epistemology, and is philosophically grounded in constructivism and naturalistic inquiry, valuing the variance of human experience. Research using ID methodology presents data in a thematic summary that enhances a clinician's understanding of the phenomenon, and provides practical application to clinical practice for the betterment of patients and families (Thorne, 2016).

Two-Eyed Seeing emphasizes the importance of using the best of both Western and Indigenous worldviews to interpret and understand a phenomenon (Bartlett et al.,



2012). The study was guided by Two-Eyed Seeing since inception through collaboration with the Indigenous community, and a Métis advisor and First Nations research assistant who both provided an Indigenous “eye” on the research process, including data analysis. Details of how Two-Eyed Seeing was applied to this study will be described in another publication.

Andersen’s *Behavioral Model and Access to Medical Care* (1995) was used to develop the interview guide and selection of study variables. Andersen’s model describes numerous factors that together influence one’s access to health care, including environmental (health care system and external societal factors), characteristics of the population (predisposing individual characteristics, enabling resources and need), health-related behaviours (health choices and use of health services) and the health status of the individual (Andersen, 1995).

### **Scaffolding**

The researcher is encouraged to reflect on their beliefs and values when undertaking research using ID (Thorne, 2016), and to disclose their worldview to the reader when working with Indigenous communities (Lavallée, 2009). Briefly, the first author is a non-Indigenous nurse researcher of European settler descent who recognizes her Western biases and unearned privilege associated with being part of the majority, mainstream society. She is passionate about eliminating inequities experienced by Indigenous people in Canada and completed her PhD studies to gain the necessary knowledge and skills to benefit Indigenous people. She hopes to be viewed as an ally to Indigenous people as she advocates for equitable access to health care.

## **Sampling Techniques**

How Indigenous mothers experience selecting and using ACS was informed by a purposeful sample. Inclusion criteria for participant mothers was comprised of self-identifying as Indigenous, living in Hamilton and caring for an infant younger than two years of age. This age was selected to ensure adequate time and opportunity for mothers to use health services in a variety of contexts and for numerous reasons, including routine well-baby checks, vaccinations and common newborn illnesses. The initial goal was to recruit a sample of 30 mothers and recruitment strategies included posters, flyers, and through word of mouth. Purposeful and theoretical approaches to sampling were undertaken to locate mothers who had experienced the phenomenon, and to explore inquiries resulting from concurrent data analysis (Patton, 2015). Snowball sampling occurred later in recruitment to locate new participants, as suggested by mothers who took part in interviews (Patton, 2015).

The perspectives of health providers were elicited to provide further context to the mothers' experiences and to help in triangulating the data. Their data are reported elsewhere (Wright, Jack, Ballantyne, Gabel, & Wahoush, Submitted October 15, 2018 to the International Journal of Qualitative Studies on Health and Well-being; Wright, Jack, Ballantyne, Gabel, Wahoush, Submitted October 15, 2018 to the International Journal of Qualitative Studies on Health and Well-being).

## **Data Collection**

Data were collected from the mothers using semi-structured interviews facilitated by ecomaps and a discussion group. Interviews occurred at a convenient location for the

mothers and lasted approximately 90 minutes. Ecomaps were used to visually depict the interview discussion. These maps serve to visualize the structure of the family, and social relationships with various systems in life (Hartman, 1995; Rempel et al., 2007). Initially stemming from systems theory and ecology, ecomaps have been widely used by social workers and nurses to demonstrate the flow of resources to and from a family (Hartman, 1995; Stewart & Allan, 2013), and with Indigenous people, in the areas of mental health and spirituality (Elliott, 2012; Hodge & Limb, 2009; Stewart & Allan, 2013). In this study, the use of ecomaps facilitated returning to topics not adequately explored and provided a visual reminder of what had been discussed.

Following initial data analysis, all 19 mothers were invited to take part in a discussion group and eight joined. The discussion helped to validate the researcher's understanding and interpretation of information, approve the interpretation of the results, and clarify further questions resulting from initial analysis. Although member checking is not required when using ID, this technique ensured the interpretations of the data were accurate, particularly as the researcher does not have Indigenous lived experience. All interviews and discussion records were transcribed and uploaded into NVIVO 12 for analysis (QSR International, 2018). Field notes provided additional context for understanding the transcripts. All data were stored in a locked office at the University or on a password-protected computer in a locked office.

### **Data Analysis**

Data analysis occurred collaboratively, guided by Two-Eyed Seeing, with the researcher and research assistant conducting analyses independently and then collectively

to compare and contrast findings. Interview transcripts were read and reread to gain a thorough understanding of the data, and only broad coding techniques were used until both researchers were fully engrossed (Thorne, 2016). Coding techniques, including values, structural, descriptive, concept and pattern coding as described by Saldana (2016), were applied to help with pattern recognition, and to explore potential relationships and meanings. Using both Indigenous and Western perspectives, the data were interpreted and developed into a thematic summary to bridge both worldviews and to help clinicians understand how Indigenous mothers experience using ACS for their infants. A full explanation of the study's methodological rigour is available in another publication (Wright, Jack, Ballantyne, Gabel, & Wahoush., Submitted October 15, 2018 to the International Journal of Qualitative Studies on Health and Well-being).

## **Results**

A total of 19 Indigenous mothers shared their experiences of the phenomenon. Their average age was 28 and one-third of whom were first-time mothers. Fifteen mothers identified as First Nations, two identified as Métis and two were not sure. Demographic information is presented in Table 1: Demographic information: Participant mothers. The results described here depict how Indigenous mothers select ACS for the care of their infants, followed by a thematic summary of their experiences using ACS to meet the health needs of their infants.

### **Selection of Acute Care Services**

Mothers sought care for their infant's urgent health conditions by attending the ED, community walk-in clinics and/or using telehealth. They had not used urgent care

centres to meet their infants' health needs. Reasons for using ACS included emergency medical treatment, health education for unfamiliar ailments, and for reassurance that their infant was well, and that their care was appropriate. All mothers preferred the children's ED that specialized in infant and child health and offered the medical expertise, equipment and services their child might require. One family used a community walk-in clinic in place of primary care because they did not have a primary care provider. Finally, telehealth services, with access to nurses 24 hours a day, seven days a week via telephone, provided reassurance to mothers on how best to care for their infant's ailment. Most often mothers were counselled to attend the ED where an in-person assessment of their infant could take place. All mothers reported they had attended the ED despite receiving assurance from telehealth services that their infant did not require ED care. This was because they did not feel confident in their ability to communicate their infant's condition adequately to the telehealth nurses, and they needed reassurance their infant was safe.

### **Experience of Using Acute Care Settings**

Analysis of the data from mothers about their experiences of using ACS to meet the health needs of their infants resulted in six themes. These included: (a) problematic wait times; (b) acute care is costly; (c) children's specialty; (d) trusting relationships; (e) racism and discrimination; and (f) holistic care. The acute care context from which these themes originated provides important implications for health providers who want to understand both the experiences of Indigenous mothers caring for their infants in these settings, as well as how best to apply these lessons to clinical practice.

**Problematic wait times.** Mothers described frustration at long wait times at the ED and walk-in clinic. Long wait times were prohibitive for mothers who, in some cases, might prefer to wait for an appointment to see their infant's primary care provider to avoid this. One mother described her frustration with wait times:

...A lot of people say that [the children's hospital] is the best hospital here in town. Ya, they do their job good and they provide the stuff that they are supposed to, but it is that the wait that these children have to wait. Especially the ones that are really, really ill. That is what gets me is because it is like you are waiting there and your child is screaming. The body heat that is coming out of them. They are pooping and throwing up, and this and that. It is like you get frustrated because they're frustrated. Yes, I try not to, but it is kind of hard not to when your child is there screaming and crying. Everything, you just want to walk away.

Some mothers used telehealth or a walk-in clinic to avoid long ED wait times. However, despite this, mothers who used telehealth did not feel reassured until their infant was seen in person by a health professional, most commonly at the ED. One mother explained why she would rather have her infant seen by a health provider than speak on the phone to telehealth:

Basically, I tell them the symptoms and they will tell me it is nothing serious. They said you can just check up to make him feel better, but they will not give you anything for it... I feel better knowing that there is nothing like seriously wrong, but I still end up going [to the ED] anyways just because I need a second opinion. Like over the phone, what if something is really wrong or I missed a symptom or something?

Finally, when mothers waiting for care with their infants perceived inappropriate staff behaviour, they became angry, frustrated and lost trust in their infant's acute care provider (ACP). Many mothers described seeing ACPs ignore patients or inappropriately using cellphones and computers while mothers were struggling to manage their ill

children in the waiting room. One mother described how the behaviour of health providers caused her to become angry:

...most of them [health providers] they just sit around and chit chat when they are supposed to be doing their job. And that is what makes a lot of parents angry because they have to wait... you should only have to wait maybe [a] half hour to an hour. Not like five, six, seven or eight hours. Like that is just ridiculous. And kids are sitting there puking and screaming...

This inappropriate behaviour made mothers feel their infants were being neglected and caused them to dislike and mistrust ACPs. Another mother explained how she was relieved her infant did not require immediate attention after seeing an ACP use social media rather than caring for patients:

When we went there, the woman that was working the reception, she weighed her. So we had to go into where the doctor was and it bugged me because he was sitting on his computer on Facebook... So I was like okay, you're lucky my kid is not dying.

Long wait-times and unprofessional behaviour deterred mothers from seeking care, and several mothers described taking their ill infants to other EDs that lacked specialized care for children, but where staff were viewed as professional, attentive, and able to relate to them.

**Acute care is costly.** Attending an ACS can be costly for mothers. These services are not available in every neighbourhood and require some amount of travel. For the mothers in this study, attending the children's ED was financially limiting because of long rides on public transit, costly parking, or taxi fees. Some EDs alleviated this barrier by providing taxi chits for families in need to get home at night after buses no longer run. One mother described how transportation to the children's ED was a barrier to care:

It's far... like basically it is two buses, because the one bus around here only goes so far and then you have to get on another one that takes you all the way to [the children's ED]... If there was ever a real emergency I would either have to take a cab or call an ambulance. It would be just too far to scoot over there.

When asked how she would attend the children's ED if the buses were no longer running, she replied:

Usually I check beforehand to make sure on the schedule... So, if there was something after 6pm and my only option was to bus out there, I would be pretty screwed. If there were no family members available, I would have to take a cab [which] is toward the twenty-dollar range.

Community walk-in clinics were available across the city and were therefore more likely to be near where families live, lessening the need for transportation and the associated costs. Despite this, however, some mothers reported their primary care providers charged them for using walk-in clinics. These penalties were approximately \$40 to \$50 CAD per visit and carried the perception that the family was at risk of being removed from the clinic's patient roster. When infants required health care after hours, or when primary care clinics were unable to provide same-day care, mothers faced the financial burden of attending an ACS. One mother explained her dilemma of choosing to use a walk-in clinic for her infant when they were unable to be seen by their primary care provider:

...actually my doctor wasn't available. We had to take him to a different walk-in clinic, which we got billed for. Because my doctor's office they have a walk-in from five to seven but it is packed usually. So you're lucky if you even go see someone right. I didn't want to take the chance, so I went to a walk-in clinic... My doctor's office they tell you specifically do not go to walk-in clinics because you will be billed for it because they have their own walk-in clinic.

Another mother shared her experience of being penalized by her primary care



provider for using a walk-in clinic despite the clinic's inability to see her infant when they were ill:

...when I looked into that I couldn't go to a walk-in clinic. Like he was ill and he [primary care provider] couldn't get him in right? ... Well one of the parts that you fill out is a contract and it states that in that contract. Nobody told me this, you're not allowed to go to any walk-in. You're allowed to go the emergency but if you go to a walk-in clinic your doctor gets billed for that I guess. And you no longer have a doctor.

These financial burdens were devastating for mothers experiencing poverty, resulting in insufficient funds for rent or to buy food or diapers for their children. Most mothers were reliant on family members to provide rides to ACS and if possible, would consider delaying care until a ride was available because of the high cost associated with using a taxi.

**Children's specialty.** The first choice for nearly all mothers was to attend the children's ED in the city for any emergency - and for less urgent issues as well, even when these issues could be cared for by their primary care provider. In addition to the specialized equipment and treatments, the children's ED was preferred for its family-friendly waiting rooms and because the staff were familiar with caring for children. As one mother described:

In case they needed to do something, they got everything there... Just the proper machines, and like whatever. If you have to put them on oxygen, like if babies are wheezy, whatever yeah... Whether it's an x-ray machine, or if they have to do different types of checks, to check for pneumonia. And stuff like that. Just to be safe right?

Mothers perceived walk-in clinics as less than ideal for infants because they did not specialize in children's health. One walk-in clinic specifically denied care to a mother with an ill infant, stating they do not care for children under the age of five.

I am pretty sure he had thrush, and yeast rash, and I knew what it was already, and I know I can't treat it myself. And my doctor was full that day, until Monday... And then I actually got there [the walk-in clinic], and they said they couldn't look at anyone under five... You're a walk-in clinic, do you expect people not to bring children if they are ill? ... This is my first time bringing him to a walk-in clinic, and this is why I don't, right?

The children's ED had a good reputation for providing excellent care for children, and the mothers also appreciated that the care was provided in child and family-friendly ways. Mothers described waiting rooms with entertainment for children by way of interactive screens, toys and books. Chairs were appropriately child-sized, and there were activities and colourful artwork covering the walls. Staff at the children's ED understood the difficulty of waiting with children and checked in regularly, making visits as efficient as possible. Mothers were happy with how staff interacted with their infants: examinations were made less threatening by using distraction and age-appropriate communication. A mother described how the staff took a child-friendly approach with her infant:

They actually played with him before they checked him out so they don't freak him out. They had toys there to keep him happy. But when he was freaking too, so they could actually take a look at him.

The specialized approach of the children's ED made mothers and infants feel more comfortable while waiting and confident in the care they would receive.

**Trusting relationships.** Although mothers in this study visited ACS infrequently, they desired to feel trust and rapport with their infant's ACP, regardless of how often they interacted with them. Mothers described three components of building trusting relationships with ACPs, including: effective communication, reassurance and thorough assessments. They described essential ACP communication skills as listening well and

validating mothers' concerns; describing assessments, diagnostic tests, and treatment plans; and providing anticipatory guidance on how the mother might continue to care for her infant at home.

Second, mothers wanted ACPs to provide reassurance; that the infant was in the hands of an expert, that the mother's concerns for her infant's health were valid and that she can care for the infant with appropriate treatment and monitoring. One mother described her need for reassurance:

No, he didn't get treated or anything, but it eased my mind, right? I needed to know, just for my sake... Okay well you're doing everything, he's fine. Just keep doing what you're doing... But I didn't know if it was something worse, so I had to make sure.

Third, mothers also wanted to see that their infant was thoroughly assessed. When their infant's ACP did not physically assess their infant, perform diagnostic tests or if mothers left the ACS without a prescription, mothers felt as though their concerns had been dismissed and their child neglected.

I would rather them look into it a lot more better. It's like they come in, then they are in there for like five minutes then they are gone. I thought when you take a baby in there they are supposed to do all these tests on them no matter how long it takes. Like blood tests, or urine tests. And other kinds of tests that they do with kids.

While mothers recognized that building trusting relationships was difficult in ACS, effective communication, providing reassurance and thoroughly assessing their infant helped to facilitate feelings of trust and building a relationship with their infant's health provider.

**Racism and discrimination.** Any experiences of racism or discrimination quickly dissolved a mother's trust in her infant's ACP. For example, a few mothers described

feeling judged due to their history of substance abuse, and despite their sobriety, found themselves confronted by this history at each visit to ACS. Some mothers attribute an ACP's reference to past drug use, or involvement with child protection services, as directly linked to being Indigenous. One mother describes her experience of feeling judged:

It was just traumatizing. And on top of it both of my grandparents were raised in residential schools here in Canada, so that was just hell growing up on its own. You know? I didn't know how to cope, and I wasn't taught. I wasn't in counseling, nothing. And I had lost my kids, which I should have, long before I did because I was an addict and I was neglectful. It was really bad you know? I think that kind of stuck with me unfortunately. It like leaves a mark on you, that no matter, clean five years. Five babies, and all my babies live with me. Pediatrician's like: "You're good to go" you know? Good relationships with their teachers. My older three are getting awards, but it still sticks with you. It does because of their [hospital] charts. right? And they open it up and they are like hmm. And I am like whatever, you can't live through half of what I have lived through, and I am here.

Experiences of racism and discrimination left mothers feeling judged, shamed and distrustful of their infant's ACP, and severely limited rapport and the potential for building relationships with ACPs.

**Holistic care.** As specialized services, ACS face challenges in providing holistic care. Despite this, however, mothers desired for ACPs to provide holistic care as best as possible. This included meeting their infant's physical, emotional, mental/developmental, and spiritual health needs. Every mother described their infant's ACP as able to meet their infant's physical health needs, but not their emotional, mental/developmental or spiritual health needs. Four mothers felt their infant was too young to have spiritual health needs, and those who believed their infants did have spiritual health needs wanted ACPs to meet these. Some suggestions for ACPs were to let mothers know where to engage in

ceremony - such as smudging - ideally by showing them where spiritual rooms such as chapels were available. Another idea was to have an Indigenous Elder on-site or easily accessible. One mother shared her suggestions:

That is probably what they do need in the hospital is an Elder there. Where I come from they have all of that in there. Like they have a spiritual room or sacred room and my mom drums there and goes there every week.

Mothers did not expect their ACP to provide their infant with traditional medicine but expected providers to recognize spiritual health needs as important, to ask whether their child had outstanding spiritual health needs, and to help them meet those needs by linking them with on-site or other community resources. Another mother described how she believed ACPs could better provide for her infant's spiritual well-being:

... it's like you can't explain that to them because they look at you like your friggin crazy. Like, "What do you mean you don't need medication? You need a ceremony?" You know what I mean? Like because they're so fast to push pills and their type of therapies. So them being in contact like I said before, with some Elders within our community to get recommendations, you know what I mean? Different approaches and stuff.

Collectively these six themes provide concrete examples of how ACPs can improve access and promote positive health care interactions for Indigenous mothers and infants using ACS.

## **Discussion**

This study is the first to explore how Indigenous mothers living off-reserve in urban areas access health care for their infants, and the results have important implications for care delivery within ACS. Many mothers shared their need to be reassured by ACPs that they were caring for their infants appropriately and that their children were well. This often resulted in their seeking immediate care at ACS,

particularly when primary care providers were unable to see their infant on the same day concerns arose. Using ACS were financially burdensome, resulting in fines or costly taxi fares to attend the children's ED. Mothers spoke to the importance of building relationships with ACPs and that incidences of racism or discrimination destroyed the potential for building rapport. Finally, mothers shared their desire for receiving holistic care in ACS and provided practical ways for ACPs to care for the spiritual health of their infants, despite the setting's potential limitations of doing so.

The use of a culturally safe approach can assist ACPs in meeting these needs. By minimizing inequities, a culturally safe approach can positively impact health care access and mitigate further harm resulting from insensitive health provision and destructive policies. The findings of this study will now be described through a lens of cultural safety, including the important application of trauma and violence-informed care (TVIC) principles.

Culturally safety was first described by Maori women in New Zealand who identified the need for health professionals to provide culturally safe care to Maori patients (Papps & Ramsden, 1996). This is achieved in a series of steps. The first is for health providers to become culturally aware by recognizing the differences between their own lived experiences, beliefs and values and how these differ from people they care for (Koptie, 2009). Health providers must then strive to become culturally sensitive, identifying how their own biases might impact their care (Koptie, 2009). Next, health providers deliver culturally competent care when they gain the ability to think critically about their interactions with patients, understanding that one's circumstances and

worldview influences behaviour and health outcomes. Ultimately what is considered culturally safe care can only be affirmed by the patient, based on their experience of feeling truly safe (Papps & Ramsden, 1996).

A mother feeling insecure as a parent, and with a need to seek reassurance at ACS -demonstrated in this study - may reflect the impact of ongoing trauma in their life. A culturally safe approach to care embodies TVIC principles, as health providers examine how their own values and beliefs, in conjunction with health policy, may result in harm to patients (Varcoe et al., 2016). The mothers in this study faced social inequities that led to poverty, lower educational achievement, insecure housing and other challenging social situations. While these inequities did not affect everyone in the same way, they negatively impacted parenting for some. The presence of these inequities may create a societal misperception of a mother's ability to parent, which collectively contributes to the over-representation of Indigenous children in the care of child protection services (The Truth and Reconciliation Commission of Canada, 2015). Coupled with the history of residential schools and the sixties scoop, the involvement of child protection services can trigger historical trauma for mothers, while also developing new experiences of trauma. Mothers' frequent reliance on the ED for reassurance in this study may be attributed to their involvement with child protection services and their resulting fear of child apprehension if they were viewed as neglectful of their infant's health. This insecurity may also stem from feelings of inadequacy as a parent, reinforced by the involvement of child protection services in their lives. Recognizing this potential for trauma, health providers can apply TVIC principles by providing respectful and non-judgmental care, and affirming a

mother's strengths and abilities as a parent (Catallo et al., 2013; Markoff et al., 2005; Varcoe et al., 2016).

Mothers emphasized how using ACS was financially burdensome. This finding is consistent with the literature that also suggests the financial burden associated with using some ACS can be extremely prohibitive for mothers on a fixed income who are seeking urgent care for their infant (Browne & Fiske, 2001). Poverty is an example of structural violence caused by an inequitable distribution of wealth that is exploited by the imposition of fines for using walk-in clinics and cost-prohibitive transportation and parking fees (Browne & Fiske, 2001). By applying TVIC principles, ACPs can support families in financial need by waiving fines, providing taxi reimbursements, bus tickets and affordable parking.

Indigenous mothers who have experienced racism and discrimination in the health care system have difficulty trusting health providers (Denison et al., 2013; Smith et al., 2006; Van Herk et al., 2011, 2012). This mistrust is warranted given the history of the residential school system and Indian hospitals, where many Indigenous people were sent and never returned (The Truth and Reconciliation Commission of Canada, 2015). Building trusting relationships with their infant's ACP was important to mothers despite the potential challenges in busy ACS environments, where care tends to be episodic and relationships are thus difficult to establish. Mothers shared that such relationships were possible when ACPs had effective communication skills and involved them in decision-making. They also felt more comfortable when they were provided with reassurance using a strength-based approach, and when their concerns were validated. A qualitative



study of First Nations women's experiences accessing health care found similar findings; women desired to be actively involved in decision-making about their health and wellness (Browne & Fiske, 2001). The literature demonstrates that if the concerns of Indigenous women are disregarded, they may refuse to seek care in the future (Kurtz, Nyberg, Van Den Tillaart, Mills, & The Okanagan Urban Aboriginal Health Research Collective, 2008). It remains unknown whether this disregard also leads to delaying or refusing to seek care for their infants. Past negative encounters with health providers was not demonstrated in a study by Van Herk et al. (2012), however this is the only study to date to explore this issue. Because all study participants were involved with child protection services, the mothers may have felt unsafe disclosing that past negative encounters with health providers impacted how they sought health care for their infants. The possibility that this occurs, therefore, remains plausible. Indeed, in our study, two mothers disclosed how negative encounters with ACPs at the children's ED led to their decision to go to other EDs in the city, even though these did not provide specialized care for children.

Using a strengths-based approach is another way ACPs can provide culturally safe care, and has been advocated for in the literature when caring for Indigenous women and their children (Smith et al., 2006; Van Herk et al., 2011, 2012). As desired by the mothers in this study, ACPs can build a mother's confidence in her parenting by helping her find her voice through listening, validating her concerns, and actively engaging her in decision making. Building on strengths, like a social network, knowledge of their infant's health, and their ability to problem-solve, helps to improve self-esteem and encourages mothers to return for future care (Smith et al., 2007, 2006, Van Herk et al., 2011, 2012).

The presence of social support has been demonstrated to assist mothers in attending their prenatal appointments (Heaman et al., 2014). Conversely, another study found that more than a quarter of mothers with little or no social support reported difficulty accessing health care for their infants (Brandon et al., 2016). Mothers in this study commonly spoke of their reliance on family members to get them and their infants to ACS. Taking a strengths-based approach, ACPs can use social networks as a strength on which to build confidence and encourage mothers in their parenting skills. When mothers lack a social network, ACPs can positively reinforce how relationships offer a mother support and an ability to care for her infant during a health care interaction.

Mothers valued the provision of holistic care for their infants, regardless of challenges of delivering this in ACS. Mothers reported, however, that ACPs addressed only their infant's physical health - and not their mental/developmental, emotional or spiritual health needs. This perception may in part be due to a lack of communication on the part of ACPs, as mental/developmental health are commonly assessed by observing infant movement and behaviour during other assessments of an infant. Acute care providers may not share their findings with mothers, leaving mothers to believe these needs had not been assessed when they had. Addressing the emotional needs of infants may prove difficult in an ACS where mother-infant attachment and her recognition of infant emotional cues takes time to evaluate, and where interactions with ACPs are brief. In addition, there remains a lack of research describing how best to assess infant emotional health, and thus ACP expertise may be lacking (Bagner, Rodríguez, Blake,

Linares, & Carter, 2012). Regardless, the mothers in this study wished to be asked about infant bonding and their need for support.

Some mothers also wished for spiritual care be valued as an important component of infant health, and that ACPs ask mothers about these needs during the health care encounter. While most participants did not expect their infant's ACP to offer natural therapies or traditional medicine in an acute care encounter, they wanted their infant's ACP to link them with Indigenous Elders, on-site spiritual care rooms, and other cultural resources in the community.

In summary, the mothers in this study described examples of positive ways that ACPs facilitated access to ACS and provided for the urgent health needs their infants. The children's ED provided an excellent application of family-centred care, with age-appropriate entertainment and furniture in waiting rooms and the use of effective communication skills with mothers and their children. There remain areas for improvement, which may be implemented through the application of culturally-safe and TVIC approaches to care. When cognizant of these two approaches, ACPs are better able to consider the role of poverty in the lives of their patients and act accordingly as they provide care. Similarly, ACPs who appreciate the impact of colonization on Indigenous people, are better situated to provide care free from racism and discrimination. Finally, ACPs can better provide for the spiritual health needs of infants by acknowledging that these needs are important for some, and by linking families with community resources as appropriate. On-site, ACS can support staff and families by providing spiritual resources,

such as safe spaces for traditions and ceremonies to take place, as well as access to Indigenous Elders.

The provision of culturally safe care is mandated through the Truth and Reconciliation Commission (TRC) (The Truth and Reconciliation Commission of Canada, 2015) and its Calls to Action. All levels of government, health organizations and educational institutions are developing policies to support the TRC's recommendations. Government funding must first be realized to support culturally safe education and practice changes. Second, the availability of quality cultural safety programming, developed in consultation with Indigenous advisors and Elders, is necessary for health care organizations and for educational institutions to train staff and students. While some Indigenous cultural training programs are currently available in the provinces of British Columbia and Ontario (Provincial health services authority British Columbia, 2018; Southwest Ontario Aboriginal Health Access Centre, 2018), costs and limited enrollment may be prohibitive for large institutions. Third, health care organizations require policies that facilitate the availability of cultural and spiritual spaces for traditional ceremonies to take place. An effective enactment of policies such as these will enable health providers to provide culturally safe and TVIC care in ACS.

### **Strengths and Limitations**

This was a small study of 19 Indigenous mothers, and although data collection continued until conceptual redundancy was attained, each lived experience differed, and it is not possible to capture every variation in experience (Thorne, 2016). It is important, then, that health providers to consider the uniqueness of each family. Second, the

perspective of fathers was not elicited, as nearly 30 percent of Indigenous children under the age of four live in families led by a single mothers (Statistics Canada, 2017b).

Nevertheless, the experiences of Indigenous fathers may have important implications for health care delivery. Thirdly, the experiences of Indigenous families whose infants required admission to hospital, long-term in-hospital care, or the use of specialty health services was not discovered in this study, due to recruiting difficulties, and are also important to understand. These findings will have implications for Indigenous infants living both on and off reserve, as a lack of specialized services on-reserve often requires families to seek care in off-reserve urban settings.

### **Future Research**

This research contributes to the scarcity of understanding concerning how Indigenous mothers access health care for their infants and the barriers and facilitators to this access. Future research is needed to determine whether interventions may effectively improve this access and how these improvements may impact health outcomes. Understanding how health services can better support Indigenous infants who frequently use health services for chronic conditions or require admission to hospital is also necessary. Finally, considering the perceptions of health providers caring for Indigenous people can support transforming knowledge into practice.

### **Conclusions**

The TRC Calls to Action mandate that health services in Canada work to improve health outcomes for Indigenous people and provide culturally safe care (The Truth and Reconciliation Commission of Canada, 2015). Findings suggest that culturally safe care

in ACS includes recognizing how social inequities and structural violence result in trauma and subsequent harm for Indigenous mothers and infants as well as differences in how they access and use health care. Adopting culturally safe (Papps & Ramsden, 1996) and TVIC (Varcoe et al., 2016) approaches to health care provision can promote equitable access to health care, and promote positive interactions between ACPs and Indigenous mothers and infants. These improvements to the provision of acute care services may then result in improved health outcomes for Indigenous infants and their families.

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Table 1

*Demographic Information: Participant Mothers*

<b>Variable</b>	<b>Category</b>	<b>Frequency (%)</b>
Age	<25 years	5 (26)
	26-30 years	8 (42)
	>31 years	6 (32)
Number of Children	First time moms	5 (26)
	2-5 children	14 (74)
Education	Less than High school	9 (47)
	Completed only high school	3 (16)
	Some College/University	7 (37)
Marital Status	Single/Separated	9 (47)
	Married/Common-law	10 (53)
Indigenous Identity	First Nations	15 (78)
	Métis	2 (11)
	Inuit	0 (0)
	Unknown Indigenous heritage	2 (11)
Income	Full-time Employment	7 (37)
	Ontario Works (social assistance)	10 (53)
	Disability Pension	2 (10)
Change of address during life of infant	Moved at least once	10 (53)
	Same residence	9 (47)
Regular Health Care Provider	Family physician	17 (90)
	Pediatrician	1 (5)
	None	1 (5)

*Note.* N=19. Adapted from Wright, Jack, Ballantyne, Gabel, & Wahoush, Submitted October 15 2018 to the International Journal of Qualitative Studies on Health and Well-being. Currently under review.

## **CHAPTER FIVE**

**TITLE:** How Indigenous Mothers Experience Selecting and Using Early Childhood Health Promotion Services in Hamilton, Ontario to Care for Their Infants

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### Abstract

**Purpose:** Promoting a child’s healthy growth and development in the first six years of life is critical to their later health and well-being. Indigenous infants experience poorer health outcomes than non-Indigenous infants, yet little is understood about how parents access and use health services to optimize their infants’ growth and development.

Exploring the experiences of Indigenous mothers who select and use early childhood health promotion services provides important lessons into how best to promote their access and use of health services.

**Methods:** This qualitative interpretive description study was guided by the Two-Eyed Seeing framework and included interviews with 19 Indigenous mothers of infants less than two years of age and 7 providers of early childhood health promotion services.

**Results:** Mainstream (public) and Indigenous-led health promotion programs both promoted the access and use of services while Indigenous-led programs further demonstrated an ability to provide culturally safe and trauma and violence-informed care.

**Conclusions:** Providers of Indigenous-led services are best suited to deliver culturally safe care for Indigenous mothers and infants. Providers of mainstream services, however, supported by government policies and funding, can better meet the needs of Indigenous mothers and infants by providing cultural safe and TVIC.

Promoting adequate growth and development in the first six years of a child's life is critical to health and well-being in adulthood (Hertzman, 2000). Self-confidence, language and cognitive skills are achieved during this important period of development and result in readiness for school (Hertzman, 2000). Children who do not develop these skills are more likely to experience lower academic achievement, social and behavioural issues, mental health issues and are less successful as adults (Hertzman, 2000). Health promotion during early childhood is therefore imperative to assist parents in optimizing the healthy growth and development of their children during these critical years. In Canada, early childhood health promotion services are provided provincially by public health departments and community services, and commonly consist of parenting classes, programs to promote parent/infant attachment, home visitation services and play groups. Overwhelmingly, participation in these programs is voluntary. Thus, developing a deeper understanding of how parents, specifically mothers, who typically provide for the health needs of their infants, select and use these programs, will give us insight about the factors that promote their accessibility and use.

This article is part of a larger study exploring the phenomenon of how Indigenous mothers living off-reserve in the city of Hamilton, Ontario, experience selecting and using health services to meet the health needs of their infants aged less than two years. The broader study included 31 participants, comprised of 19 mothers, five primary care providers and seven providers of early childhood health promotion services. Results presented in this article describe the experiences of mothers specifically related to their use of early childhood health promotion services to promote the healthy growth and

development of their infants. The findings provide transferable strategies to promote the accessibility and use of health services for Indigenous infants and their families in other areas of the health care system.

### **Health of Indigenous Mothers and Infants**

Indigenous infants and families in Canada are uniquely disadvantaged by social inequities, racist and discriminatory policies that may lead to difficulties when they access and use health services (C. Reading, 2015). This results in poorer health outcomes for some (C. Reading, 2015). Literature supports that many Indigenous people experience higher rates of chronic disease, poverty and injury than non-Indigenous people (Greenwood et al., 2015). Indigenous women experience three times the rate of violence, higher rates of poverty, diabetes, human immunodeficiency virus (HIV) and are more likely to single parent than non-Indigenous women (Amnesty International Canada, 2014; Smylie & Adomako, 2009; Van Herk et al., 2011). Indigenous mothers have higher incidences of gestational diabetes and hypertension in pregnancy, and resultant abnormal birth weights that increase their infant's risk for developmental delay, learning difficulties, hypertension, diabetes and other chronic conditions later in life (Tarlier et al., 2013). Indigenous infants experience higher rates of birth injury, morbidity and infant mortality than non-Indigenous infants and are at higher risk for admission to hospital (Smylie et al., 2010; Van Herk et al., 2011). While these are consistent findings in the literature, it is important to use caution when interpreting the health outcomes of Indigenous people as data are typically aggregated, do not distinguish between First



Nations, Inuit and Métis groups and may under-estimate findings due to low participation rates, and reluctance to self-identify as Indigenous (Smylie et al., 2011).

The poorer health outcomes experienced by many Indigenous people, particularly women, are a direct result of the lasting impacts of colonization and the implementation of the Indian Act in 1876. This policy disproportionately disadvantaged Indigenous women. Indian status passed on to children only through fathers, women were denied involvement in band government, and any Indigenous woman who married a man without status lost their own status and any associated benefits, such as the right to live on reserve land (Native Women's Association of Canada, 2007). This policy resulted in a paternalistic hierarchy which benefited men, and this gender inequality subsequently resulted in poorer health outcomes for many Indigenous women (Barker, 2008).

A recent initiative to collect accurate and representative data for Indigenous people in Canada provided a valid representation of the health status and health service use of First Nations people living in Hamilton, Ontario (Smylie et al., 2011). The findings demonstrated that compared to the general population, First Nations people living in this city had a higher rate of diabetes (15.6% compared to 4.9%) and hypertension (25.8% compared to 19.7%), as well as a larger proportion of individuals who reported fair or poor mental health (36% compared to 10% of those ages 12 years and older living in cities in Ontario) (Smylie et al., 2011; Statistics Canada, 2018). Many First Nations people experienced poverty, with 70% living in Hamilton's lowest income neighbourhoods, compared to 25% of the non-Indigenous population as a whole (Smylie et al., 2011). Extreme poverty and inadequate housing represents a mode of structural

violence, resulting in harm and trauma for those affected, and also leads to food insecurity and other social inequities (Moore et al., 2015; Varcoe et al., 2016). Indeed, First Nations people living in Hamilton reported high rates of overcrowding (73.7% compared to 3% of Canadians) and difficulties obtaining adequate amounts of food (63% report not buying food in order to meet shelter-related needs; 22% reported sometimes or often not having enough food to eat) (Smylie et al., 2011). Social inequities affecting parents also result in deleterious effects on the health of their children. Parents reported high rates of asthma (14.9%) and chronic ear infections (14%) in their children and 22% reported concerns for their children's development and for their physical (56.2%), mental (38.2%), and emotional (54%) health (Smylie et al., 2011). From a cultural perspective, 94% of parents felt that traditional events were very or somewhat important to their children's life (Smylie et al., 2011).

Ongoing and historical trauma can negatively impact the health of Indigenous families. Trauma results when unexpected events occur that surpass an individual's ability to cope (Manitoba Trauma Information Centre, 2018a). Indigenous people uniquely face historical trauma stemming from colonization, and the racist policies which led to the residential school system and the apprehension of thousands of children by child protection services during the sixties scoop. Within the health care system, Indigenous people continue to experience racism, discrimination and a lack of respect for the role of traditional ceremonies and medicine in health and well-being (The Truth and Reconciliation Commission of Canada, 2012). Ongoing trauma also results from social inequity and interpersonal abuse, violence and suicide that greatly effect some Indigenous

communities (Bombay et al., 2009; Manitoba Trauma Information Centre, 2018b; Varcoe et al., 2016). Children may experience developmental and intergenerational trauma, where subsequent generations can continue to be impacted by colonization (Manitoba Trauma Information Centre, 2018b; Moore et al., 2015).

Social disadvantage and trauma negatively impact a child's health, setting the trajectory for reduced health and well-being in adulthood and beyond. Trauma causes long-term physiological and neurological consequences in children, altering stress responses, resulting in depression, chronic diseases, and substance use in later life as victims attempt to cope with these effects (Bombay et al., 2009; Moore et al., 2015). Children growing up in economically disadvantaged neighbourhoods have reduced access to parks or green space, and face greater exposure to environmental toxins, air pollution, and noise that negatively impacts brain development, psychological well-being and educational achievement later in life (Moore et al., 2015). Abuse, neglect, parental substance use, homelessness and violence interrupt parent-infant attachment, further contributing to adverse impacts of social inequity on early childhood development (Moore et al., 2015).

### **Importance of Early Childhood Health Promotion Services to Development**

Access to high-quality early childhood health promotion services is extremely important to mitigate the effects of social inequity and trauma on the development and subsequent health outcomes of infants. Early childhood health promotion programs, offered to women during pregnancy and to parents of infants and young children, support forming healthy bonds and attachments between parents and infants, provide nutritional

and other health-related education, and promote positive parenting and healthy play – all leading to the healthy neurophysiological and psychological development of infants (Moore et al., 2015). Research has demonstrated that by supporting early learning, early childhood health promotion services are an excellent strategy to promote equity for families facing disadvantage, and promote improved school readiness (Moore et al., 2015).

How these services are provided is key to promoting access and use by infants and families. Educating parents about healthy nutrition and child development is associated with improved child health outcomes (Moore et al., 2015). Similarly, offering this type of education in engaging ways and facilitating communication by using text messaging, for example, effectively involves mothers experiencing poverty and encourages retention (Song et al., 2013). Home visits are another way to engage socially disadvantaged families, as they provide care where families live, and also reduce transportation and child-care related barriers to programming (Moore et al., 2015). Finally, the provision of culturally-relevant programming for Indigenous infants and families supports resiliency, protecting against mental health issues later in life, and promoting self-esteem and well-being (Priest et al., 2012). Despite these potential benefits, and although 38% of First Nations parents in Hamilton, Ontario reported that culturally-appropriate health promotion programs were a strength of the community, few were engaged in these services with their children (1.4 to 27%) (Smylie et al., 2011).

**Early childhood health promotion services in Ontario.** To promote optimal parenting and to support the healthy growth and development of infants and children, the

province of Ontario has invested in a range of health and social services programs. These services include – among others – lactation consultants, pharmacists, dieticians, community home-care offered by the Local Health Integration Network (LHIN) and infant development programs for those with disabilities or at risk for delay (Ontario, 2016a). This paper focusses specifically on findings that relate to the experiences of Indigenous mothers selecting and using mainstream programs (Ontario Early Years and Ontario Healthy Babies Healthy Children (HBHC) program) and Indigenous-led programming (Early Years, HBHC and mother-infant classes at the Indigenous Friendship Centre (IFC) in Hamilton) to promote the health of their infants. See Table 1: Early Childhood Health Promotion Services in Ontario for a brief description of each.

Briefly, the Ontario Early Years program offers community-based and engaging family programs for parents and children focused on parenting support, early childhood learning, and parent education on child health and development (Ontario Ministry of Education, 2018). Second, in the Ontario HBHC program public health nurses (PHNs) conduct health-related screening and developmental assessments of infants to facilitate healthy development and mother-infant attachment, and links families with community resources and supports (Ontario Ministry of Children Community and Social Services, 2016).

Table 1

*Early Childhood Health Promotion Services in Ontario*

	Ontario Early Years	Ontario HBHC Program	Early Years	HBHC	Mother-infant classes at IFC
	Mainstream Programs		Indigenous-led Programs		
<b>Funding</b>	Ministry of Education	Ministry of Children and Youth Services Delivered by Public Health Ontario	Ministry of Education	Aboriginal Healing and Wellness Strategy	National Association of Friendship Centres
<b>Aims</b>	-Parenting support -Early childhood learning -Parent education on child health and development	-Health screening -Developmental assessments -Healthy mother-infant attachment -Link to community resources and supports -Home visiting	-Same as Ontario Early Years -Indigenous teachings, traditions, ceremonies and resources	-Healthy mother-infant attachment -Healthy infant growth and development -Resources and supports -Family advocacy -Indigenous teachings, ceremonies and resources	-Assist urban-dwelling Indigenous families to be healthy and successful
<b>Eligibility</b>	Parents and their children under six years of age	Pregnant women & families with children under six years of age (typical length of enrollment is one year or less)	Parents and their children under six years of age	Families with at least one child under the age of six years	Families with children
<b>Enrollment</b>	Self-enrollment	a) Screening by a health provider after the birth of an infant b) Self-referral during prenatal or post-natal period	Self-enrollment	a) Identified by HBHC FHVs b) Referral from health provider c) Self-referral	Self-enrollment
<b>Expertise</b>	-Early childhood educators -Affiliated PHNs	-PHNs -Lay-person Family FHVs	-Indigenous early childhood educators -Affiliated PHNs	-Indigenous lay-person Family FHVs	-Indigenous lay-persons

Indigenous programming is uniquely designed and implemented by each province to address the needs of local Indigenous families in culturally relevant ways (Ontario

Ministry of Children Community and Social Services, 2018). In Hamilton, Indigenous-led early childhood health promotion services available for infants are offered through two Indigenous-led Early Years Centres, HBHC and mother-infant classes at the IFC. These programs are considered Indigenous-led, as they are self-governed and provide culturally relevant programming for Indigenous families in their local communities. Indigenous-led programs incorporate local Indigenous teaching and traditions, and specialize in family-violence and family advocacy (Ontario Ministry of Children Community and Social Services, 2018).

It is important to note that the Indigenous HBHC program differs significantly in three ways from the mainstream HBHC program with whom it is not affiliated despite sharing the same name. First, the Indigenous HBHC program in Hamilton is provided by only lay-person Indigenous family home visitors (FHV) and is supplemented by additional programs available at Hamilton's IFC. Second, there is no automatic referral process; mothers can self-refer or be referred by health providers or an Indigenous FHV. Third, the Indigenous HBHC program in Ontario is funded through the Aboriginal Healing and Wellness Strategy, a unique approach to the governance and provision of health care for Indigenous people in Ontario established in 1994 (Ontario Ministry of Children Community and Social Services, 2018). This strategy was the first policy in Canada to be informed by over 6000 non-Status, First Nations, Métis and Inuit people and developed a partnership model to decision-making that included both Indigenous community and government members. This strategy receives its funding from the Ontario Ministry of Children, Community and Social Services to operate several Indigenous

health programs in the province, including wellness initiatives, mental health supports, the Indigenous HBHC program and other services (Ontario Ministry of Children Community and Social Services, 2018).

This study contributes to a growing body of research regarding the accessibility and use of early childhood health promotion services by urban-dwelling Indigenous mothers and infants. The findings highlight the differences between mainstream and Indigenous-led programs and their approach to caring for Indigenous infants and their families.

### **Methods**

This qualitative study used interpretive description (ID) methodology as described by Thorne (2016), and applied the Two-Eyed Seeing framework (Bartlett et al., 2012) to integrate both mainstream and Indigenous worldviews throughout the research. A third framework, *Andersen's Behavioral Model and Access to Medical Care* (1995), informed the interview guide, and ensured all variables relating to accessing health services were explored. The research was philosophically grounded in constructivism and naturalistic inquiry (Thorne, 2016), which recognizes and values the presence of multiple viewpoints and perspectives. The study was reviewed and approved by three consulting ethics bodies including the Hamilton Integrated Research Ethics Board, the Mohawk College Research Ethics Board and the McMaster University Family Medicine program. A full description of the methodology will be published elsewhere (Wright, Jack, Ballantyne, Gabel, & Wahoush, Submitted October 15 2018 to the International Journal of Qualitative Studies on Health and Well-being).



Briefly, ID is a nursing-derived methodology that appreciates the infinite variation in lived experience that contributes to an individual's belief of truth and reality (Thorne, 2016). Interpretive description takes a pragmatic approach to inquiry, with the purpose of providing clinicians with practical applications of knowledge to benefit the health of patients and families (Thorne, 2016).

Two-Eyed Seeing was initially developed by two Mi'kmaq Elders to emphasize the need to view the world through the best of both mainstream and Indigenous perspectives (Bartlett et al., 2012). The application of this framework to the research is all-encompassing, including the community-based collaborative approach with Indigenous organizations in Hamilton, the involvement of a Métis advisor and First Nations research assistant to provide Indigenous lived-experience and perspective to the research, as well as a collaborative approach to data analysis. A full description of the application of Two-Eyed Seeing to this research will be available in a future publication.

### **Sampling Techniques**

A purposeful sample of Indigenous mothers helped to inform the understanding of how they experience the selection and use of early childhood health promotion services. The initial recruitment goal was 30 participant mothers. Inclusion criteria included self-identifying as Indigenous, living in Hamilton, Ontario and caring for an infant less than two years of age. The age of two years was selected to ensure mothers had experienced using a variety of health services to meet routine health needs, including vaccinations and well-baby checks as well as the usual illnesses experienced by infants in their first two years of life. Purposeful sampling techniques identified mothers who had experienced the

phenomenon, and theoretical sampling approaches were applied to add further depth to concepts discovered in the data (Patton, 2015). Later in recruitment, snowball sampling was employed through recommendations from participating mothers to find additional participants who had experienced the phenomenon (Patton, 2015). Mothers were recruited through word of mouth, flyers and with the help of staff at the IFC.

Later, health providers were recruited for interviews and the subsequent information helped to triangulate the data and contribute context to the mothers' experiences. Inclusion criteria included caring for Indigenous mothers and infants in Hamilton, Ontario. Recruitment strategies included phone and email invitations, along with word of mouth by the researcher and managers at community-based health organizations. The initial recruitment goal was 10 participant providers; a total of 12 providers were recruited to the study, from both primary care (n=5) and early childhood health promotion services (n=7). Data relating to the experiences of primary care health providers are discussed in another publication (Wright, Jack, Ballantyne, Gabel, Wahoush, Submitted October 15, 2018 to the International Journal of Qualitative Studies on Health and Well-being).

### **Data Collection**

The women in this study shared their experiences during semi-structured, in-depth interviews, which also incorporated the use of eco-maps. Interviews lasted approximately 90 minutes and were conducted at a convenient location for the mother, most often their home or at the IFC. During the interview, as the participants described the type of health services accessed as well as their experiences engaging with those services, these

relationships were visually documented in the form of an ecomap (Hartman, 1995). In qualitative research, the use of ecomaps has been helpful to minimize power imbalances that can exist between a researcher and participant, as both work together - often sitting side-by-side - to complete the ecomap (Rempel et al., 2007; Stewart & Allan, 2013). This technique allowed the researcher to return to areas requiring further exploration, and for mothers to easily determine which health services had been discussed and which still required explanation.

Following the analysis of the individual interview data, a discussion group took place, lasting approximately 90 minutes, to allow mothers the opportunity to confirm or dispute the presence of concepts identified during data analysis and to gain further insight and clarity on emerging ideas and themes. While not a requirement of ID methodology, member checking was important to validate the emerging findings, as the researcher did not have Indigenous lived-experience. Mothers did not ask for data to be removed and confirmed the presence of themes as identified by the researcher and research assistant. All 19 participant mothers were asked to join the discussion group, and eight attended.

Following interviews with the mothers, providers known to have experience working with Indigenous families were interviewed to further explore contextual issues relating to the mothers' experiences of using early childhood health promotion services. Providers completed semi-structured interviews lasting from 30 to 90 minutes, most often taking place at the individual's place of work or by phone.

All interviews and the discussion group were audio-recorded and transcribed verbatim for analysis using NVIVO 12 (QSR International, 2018). Data were secured in a

locked office at the University or on a password protected computer in the locked office of the researcher.

### **Data Analysis**

Data analysis was conducted by the researcher and research assistant, initially independently and then together over several months to compare ideas and concepts. The research assistant was instrumental in ensuring that cultural nuances, beliefs and values were considered during the analysis. Broad coding strategies were used initially so as to not ascribe meaning to the data until fully engaged in the process (Thorne, 2016). Applying the Two-Eyed Seeing framework ensured the analysis incorporated both non-Indigenous and Indigenous perspectives (researcher and research assistant), and in this way the meanings from mothers were promoted. The resulting thematic summary seeks to bridge both worldviews into an understanding of the phenomenon that has clinical relevance and practical application.

### **Integrity**

Thorne (2016) defines methodological rigor as integrity that is demonstrated in nine ways. First, epistemological integrity was demonstrated in this study by ensuring the entire research process was in line with the philosophical underpinnings of ID (Thorne, 2016). Next representative credibility was evident through triangulating findings with multiple data sources and literature (Thorne, 2016). Analytic logic was ensured by the presence of a supervisory committee, consisting of three nursing scholars and a Métis health researcher who collectively oversaw the research process to make certain decisions were congruent with ID and the applied frameworks (Thorne, 2016). Next interpretive

authority was established in several ways. These included: building authentic and long-term relationships with the Indigenous community prior to embarking on the research; collaborative data analysis with a First Nations research assistant; and validation by participant mothers through inclusion of ecomaps and a discussion group (Thorne, 2016). The study demonstrated moral defensibility because it aimed to benefit the health of Indigenous infants and was in line with Calls to Action outlined by the Truth and Reconciliation Commission of Canada (The Truth and Reconciliation Commission of Canada, 2012; Thorne, 2016). Disciplinary relevance was clear, as the study conformed with nursing aims to help individuals achieve their optimal well-being (Thorne, 2016). Finally, the results were presented within the context to which they applied in the following ways: to ensure contextual awareness within the limitations of their application; to exercise pragmatic obligation and probable truth; and that what is known in the moment may be disputed and determined as false should new data arise (Thorne, 2016). Collectively, the application of these nine components of integrity as described by Thorne (2016) contributed to the study's strong methodological rigour.

## **Results**

The results that follow are informed by 19 Indigenous mothers and 7 providers of early childhood health promotion services. The average age of the mothers was 28 years and one third were first-time mothers. All self-identified as Indigenous, and 15 identified specifically as First Nations, two as Métis, and two were unsure of their specific Indigenous heritage. Providers of early childhood health promotion services consisted of PHNs, FHVs and Indigenous staff at the IFC. See Table 2 Demographic information:

Participant mothers for further details including mothers' involvement with early childhood health promotion services.

The results are presented first by describing how mothers select the early childhood health promotion services they use to meet the health needs of their infants. Next, three themes that depict the care provided by both mainstream and Indigenous-led services are described, including: (a) *a comprehensive approach to care*; (b) *facilitating access through home visits*; and (c) *promoting engagement in programming*. Finally, a presentation of the four themes that related explicitly to the strategies used by Indigenous-led programs follows, including: (a) *a wrap-around approach*; (b) *building long-term trusting relationships*; (c) *holistic care*; and (d) *family advocacy*. See Table 3: Resulting Themes.

### **Selection of Early Childhood Health Promotion Services**

Given the number of mainstream and Indigenous-led infant-focused programs available to mothers in the community, we sought to identify which services participants in this study were accessing and using. This is summarized in Table 2: Demographic Information: Participant Mothers. The majority of mothers (84%) were using Indigenous-led services. The dominant services used were the mainstream or Indigenous-led HBHC programs and the mother-infant classes at the IFC. Mothers were referred to the mainstream HBHC program by health providers. Following contact by a PHN after the birth of their infants, three mothers were enrolled in the mainstream HBHC program, and two mothers received dual-care by both the mainstream and Indigenous-led HBHC programs. Mothers were enrolled in the Indigenous-led HBHC program if they were

previously known to the FHV through their involvement in cultural events or other IFC classes. Neither PHNs or other health providers had referred the mothers to the Indigenous-led HBHC program, such that FHV's were concerned that health providers in the city were unaware of their programs. One shared: "I have never really had [a referral] from a family doctor, and that could be because family doctors don't know that the program exists". Mothers who chose to attend the IFC mother-infant classes had learned about these through word of mouth or because they lived in the area.

### **Common Approaches Used by both Mainstream and Indigenous-led Programs**

**Comprehensive care.** Mothers described how providers of both mainstream and Indigenous-led programs took a comprehensive approach to care that assessed and then addressed their specific and unique needs. In particular, mothers described how providers connected them with community resources, tailored health teaching and helped with transportation barriers. One mother explained how her mainstream PHN helped her with her infant's development of speech, as well as by linking her with other community supports: "They help me like guide me in speech, they guide me in ways to deal with him. If they can't help me, they will send me to a group or something". Mothers described examples of how FHV's taught them how to promote their infants' learning through play. One mother explained, "Like last time she came, we made these things in ziploc bags. We put [in] glue and paints and taped it on my floor so he could like squish it around". Yet another mother shared how her infant's FHV assisted her with transportation: "[FHV] picked up my daughters for me one time, and [brought] me to [Ontario Works], and to go look for an apartment before I moved here". Many mothers involved with Indigenous-led

programs experienced what they described as an emphasis on providing tangible resources to support families, such as groceries, diapers or bus passes. The comprehensive approach to care by providers in both service streams met the needs of infants and mothers as required, helping some to support their infant's development, while providing necessary resources such as groceries for others. One Indigenous FHV from the Indigenous-led HBHC program described her approach to meeting the unique needs of mothers and families:

There are always unique needs. I have a client that goes to university and I can't wait for her to graduate... You know all that she really needs is someone to talk to... You know? Just that little bit of encouragement. Somebody to stand in your corner and be like "you got this"... Some are more emotional. Some need that time [home visit] to feel safe, that they can cry. So just allowing them to be individuals. Allowing everyone to have their journey and that it [HBHC program] is there for them. So I am just there to help out.

A mainstream PHN described how she individualized care through her comprehensive approach with families in the mainstream HBHC program:

It really just depends on the family needs and what their learning needs are. Things like that right? So we focus on healthy growth and development, attachment and positive parenting, but we'll support the family in other ways too. Like I said, through health teaching and connecting to community resources. Kind of just whatever they need really.

A comprehensive approach supported mothers in their parenting and promoted infant health and development through health teaching, support and resources that were directed where required.

**Facilitating access through home visiting.** The provision of care through home visiting facilitated mothers' access to the HBHC program by eliminating barriers to care. The delivery of services through home visiting offered many benefits to mothers, such as



allowing FHVs to observe the home environment, enhancing their ability to provide timely education and support, and to be responsive to the unique needs of families. Home visiting is a mode of health service delivery that is unique in that it allows the PHN or FHV the opportunity to observe the family's living environment and the nature of relationships between individuals in the home. Compared to other services, this approach allowed the FHV to directly identify infant or maternal safety hazards and provide immediate health teaching. For example, one mother shared: "[FHV] teaches me about how to take care of him properly or keeping the house baby-proof". Another mother shared how the presence of a FHV allowed her to take a shower: "She [FHV] would offer to hold baby or take the baby while I would get a shower". Yet another mother shared how her FHV helped to alleviate her anxiety over feeding her infant: "She came over the first time I fed her because I was really nervous about that. Choking or other hazards. So she was there".

Providers recognized the advantages to home visiting as well, such as taking health teaching and literature into the home rather than expecting families to make the sometimes-overwhelming effort to attend educational events in the community. One Indigenous FHV explained:

I have taken that literature into the home as well. Because if mom has six kids, let's say, you're not going to expect her to find a babysitter and come to the centre to sit for two hours. So I would take that literature and bring it to the home. Have a conversation with her based on that.

The same FHV described how home visiting also provided a type of social network to families who were otherwise isolated from friends and family:

Just talking so she has someone to bounce ideas off of and say, “This is what I’m doing”. Sort of like a validation. Some parents don’t have anyone to come over and have tea, so we will bring mom a tea. Just an extra pair of hands and eyes so she can get things done...And that is all some people need is for someone to come over and hold the baby for half an hour or forty-five minutes. Even while they go and have a shower. An uninterrupted shower.

Facilitating access to services through the provision of home visiting broke down barriers to accessing care and allowed providers to better meet the unique needs of Indigenous families; by being in the home environment, providers could better identify areas for health promotion and support.

**Promoting engagement in programming.** Providers in both mainstream and Indigenous-led HBHC programs promoted the engagement and ongoing participation of mothers in their programs by using a range of strategies. These included the use of text-messaging and incentives such as meals, and needed household items, among others. Mothers participating in the Indigenous-led HBHC program consistently described using text-messaging to ask their FHV questions related to caring for the health of their infants, such as advice on how to soothe a crying infant or how to care for a fever. The use of text-messaging allowed mothers to receive timely answers to their questions, lessening anxiety and improving their confidence as mothers. In some cases, this instant mode of feedback appeared to give mothers unrealistic expectations of their FHV. One mother shared her assumption that her FHV would be available to meet her infant’s urgent health needs when contacted via a text-message:

Like say if she has a very, very high temperature right now and I tried everything. I would call [FHV] to be honest...I can either ask her where she is or give her a text and she will come over immediately or she will drive me to the hospital.

The use of text-messaging was helpful for providers to confirm appointment times and to notify mothers if they were running behind schedule. One of the mainstream HBHC

PHNs shared her experiences of using text-messaging to engage mothers:

A lot of our moms, like you can be in the middle of a feeding or changing, and I am calling them. Like honestly who feels like listening to a voicemail and calling them back? We don't do that anymore, right?...and it is quick right?...they text me I can text them back when I have that minute. It makes it so much easier... We don't have many missed visits because we can remind them the day before.

Despite the benefits of text-messaging, it also had the potential to increase the health provider's workload beyond the regular business day. The previous HBHC PHN shared her concerns about the use of text-messaging:

We are supposed to text in office hours...For some of us though, our phone is also our personal phone...or you see a message that should be replied to...if they text saying the baby is not latching and ethically we have to reply to that. We are not going to wait until business hours. For me, I would do that anyways.

Likewise, an Indigenous FHV shared how she supports her clients outside of working hours because she empathizes with their struggles:

The latest someone called me was midnight, but I was up...I just do it because they need it...I was 17 when I had my boy, and it was a struggle. I had no supports...I was young and naïve, and whatever...I could have used them [FHV] if I knew, right? If someone would have told me. But no. So now that is who I am.

Next, Indigenous providers incentivized mothers attending their programs by offering resources that met their needs, such as meals; making crafts that were also needed as household items for their infants - making a blanket or moccasins for example; socializing with other mothers; or the provision of much-needed baby items and/or bus tickets. An Indigenous staff member from the IFC shared how she purposely provided a

meal for families in each of her classes to meet the high rate of food insecurity affecting the population she serves.

On Fridays I do [a meal program]. That is basically the biggest part, is food security. We do that on a Friday, because during the week, participants can come out and get meals at all of our programs. But on a Friday, the centre closes, so a lot have to go through making it through the weekend because they don't have enough food. I like to offer that program, so we at least know they have a meal like just for the weekend anyway.

Collectively, the provision of comprehensive care, facilitating access through home visiting and the use of text-messaging and incentives encouraged the recruitment and retention of mothers to programs, by meeting the unique needs of each family.

### **Strategies Unique to Indigenous-led Programming**

Providers of Indigenous-led programming demonstrated an awareness of the unique contextual factors affecting urban-dwelling Indigenous families beyond that demonstrated by providers of the mainstream HBHC program and used strategies to enhance access and to promote the use of services and programs by Indigenous mothers and infants. These strategies are presented by the following four themes: (a) a wrap-around approach; (b) building long-term trusting relationships; (c) holistic approach; and (d) family advocacy.

**A wrap-around approach.** First, mothers described multiple ways that Indigenous-led programs used a wrap-around approach, providing not only for the health needs of their infants, but also considering the context in which they lived, and the significant impact social inequities such as poverty and insecure housing had on the well-being of their infants. Indigenous FHV's went above and beyond, not only by providing resources, but also by driving mothers to appointments, thereby breaking down

transportation barriers to accessing services and health care. The IFC, in which mother-infant classes were held, also prioritized a wrap-around approach to meeting the needs of Indigenous families in the city. The IFC provided health promotion programs across the lifespan, as well as an on-site high-school program for at-risk youth and young adults. Those attending were able to access free internet; employment counsellors; alcohol and substance abuse counselling; specific services geared to educating and supporting families impacted by fetal alcohol spectrum disorder; and many other services. One mother described how the multiple services available at the IFC helped her complete her high school diploma:

When I try to get schoolwork done...in the front there are computers there. So I actually did some today while she fell asleep. I got on there and got a couple of things done. It's a good thing because it's free, like you don't have to sign in and stuff.

A FHV from the Indigenous-led HBHC program described her own past involvement with the HBHC program and how its wrap-around approach contributed to her success in life:

When the other woman came in [Indigenous FHV], she focused on basic needs with me. Are you comfortable being a mom?...So it was more like real stuff...like tangible things. Like what are you going to do with the rest of your life?...So I am her success story...I just started going to school and I finished college.

Collectively, Indigenous-led programs and services prioritized meeting a wide range of social inequities experienced by Indigenous families in Hamilton, in order to support and strengthen families, while also holistically caring for their health and well-being.

**Building long-term trusting relationships.** Secondly, the Indigenous-led programs aimed to build long-term and trusting relationships with mothers, infants and

families. A significant contributing factor was the longer length of enrollment in the Indigenous-led HBHC program—families consistently remained enrolled in the program so long as a child less than six years of age was in the home. The length of enrollment for families in the mainstream HBHC program was more typically a year or less. Mothers described how Indigenous FHVs prioritized building relationships, as evidenced by this example:

She'll bring games, and then we have done dreamcatchers. There is also stuff for me, like when the boys are at daycare. They don't always have to be here. Kind of like a relationship with me too. We have made dreamcatchers with the boys, and then some without. So I like doing all that. It was fun.

Several Indigenous providers shared examples of how their relationships with mothers and families become so strong, they began to feel like family. This contributed to the important goal of breaking down power inequities. An Indigenous provider from the IFC shared her perspective on the benefits of building strong relationships with the Indigenous families with whom she worked:

I find that the biggest thing for us is being able to open up with them and be compassionate. I don't know, it just feels more like we are a family with them, rather than someone that is above them. So we are kind of on their level, and there to help them kind of thing. I don't know...they feel a lot more comfortable because we are almost like their family.

Another staff member from the IFC shared how a relationship with families helped her to better meet the needs of Indigenous mothers and infants:

I try to be more like their auntie, so they can trust me and come for help if they need something. And not try to hide certain stuff or not tell me certain things. I want them to feel they can. So we can really help them, and find out what they need.

In addition to building trusting relationships between health providers and families, Indigenous-led programs also aimed to facilitate mothers building relationships with others. This was accomplished through programs that brought mothers together, often to create a craft or make a meal. One participant shared how a mothers-only program allowed her to take a break with peers:

...we can just vent because there is no kids allowed for that program. It is nice for the break. We do like crafts and stuff, and traditional beading, and we made a drum and stuff.

Another mother shared how her prolonged experience at the IFC has led to long-term relationships with others in the community:

You get to meet new people in the programs, or you already know them. So it is a nice gathering and stuff. It's like a close centre, like a lot of people you already know because they have been going there also for years.

New relationships formed at the IFC while infants were young continued to grow, as programs were offered to all age groups. A young mother described how socializing with others helped her learn more about parenting:

I just kind of tend to look and listen to other people talk about their previous experience. That is where I learn stuff...

Many mothers described enjoying events with their infant and older children. One mother described how the IFC's emphasis on forming relationships has strengthened her family:

...before, I had all these problems. I put the kids in school, go home, daycare, then go home and sit there all day...it was like we were always at home. We weren't doing anything, and the kids would be off the wall...Bringing them here has made a difference between me, [husband] and all the kids. So we're actually getting closer instead of away from each other.

Building trusting relationships was essential to foster comfort so mothers were willing to share their needs and concerns with providers, and providers were thereby better able to meet their needs. Relationships between mothers, peers and other families were equally important to supporting their parenting journeys through socializing, learning from experienced parents, and promoting family cohesiveness.

**Holistic approach.** Mothers consistently described the ability of Indigenous-led programs to provide holistic care, meaning they met the physical, emotional, mental and spiritual health needs of infants. Indigenous providers supported the physical health needs of infants by ensuring they had food to eat as well as teaching mothers how to prepare healthy meals, or to care for their infant's colds, rashes or fevers. The emotional needs of infants were met by teaching mothers how to deal with persistent infant crying or other behavioural challenges and helping them connect with and attach to their infants. Mental or developmental needs were supported by showing mothers how to promote infant development, and by facilitating infant learning through play activities and crafts.

Providers in the Indigenous-led programs also demonstrated their unique ability to care for the spiritual needs of infants, something not offered by their mainstream counterparts. Mothers spoke of participating in and learning about traditions, ceremonies and culture and that providers took part in traditions and ceremonies with them. Providers also incorporated traditional teachings into their health promotion strategies and linked mothers with cultural events. One mother shared an example of how participating in traditions with her son would help him feel a sense of belonging as he gets older:



He gets to see that he is not different. Because a lot of kids he knows don't have long hair, and don't play on drums and all that other stuff...It is good to see his nationality.

An Indigenous staff member from the IFC explained that providing opportunities for urban families to learn about their Indigenous culture was important because they had few opportunities to engage in traditions and ceremonies off-reserve. Another Indigenous staff member emphasized the importance of Indigenous identity to understanding one's path in life:

All of the classes [at the IFC] have traditional teachings with them... to find out who they are and where they come from. Like what cultural stuff they know, because a lot of them really don't know a lot. I think if you know who you are and where you come from, and your background, it makes everything else easier. Because you start to realize why you do things...what their family was like and [maybe] what they would like to see different.

Indigenous providers shared examples of how they weaved traditional teachings into the health education they provided to families. One Indigenous staff member from the IFC spoke of how she attempted to meet the spiritual needs of the infants in her program:

We do like traditional teachings on certain ways to look after baby. Traditional things that they should do...Just like naming ceremonies and the placenta. Talk about that. Even swaddling your baby and the importance of that. Breastfeeding and the importance of that.

Meeting the spiritual needs of their infants was extremely important to mothers, often a primary reason for attending Indigenous-led programs. The use of traditional medicine in ceremony and smudging was key in meeting the spiritual needs of infants. Some mothers shared their difficulty in obtaining traditional medicines in the city, and that they often relied on friends who lived on-reserve, staff at the IFC or their Indigenous FHV to get these medicines for them. One mother shared her struggle:

...Down at the Aboriginal health centre, a lot of that stuff [traditional medicine] is more readily available I guess...even getting access to traditional medicines, things like that, is a little bit harder [in the city]...it's harder to get access and stuff like that, unless you are a community member [from the reserve] and you know who to ask, right?...I just ask around really. You go to the [IFC] and you just kind of ask around.

Indigenous providers recognized how this barrier was affecting mothers living off-reserve in this urban setting and tried to make traditional medicines available for mothers wishing to take part in ceremony. One Indigenous staff member from the IFC described her approach to providing mothers with traditional medicines:

I talk about medicines as well and I tell them where they can go to get their medicines. But for some of them it is hard...so I do have a couple medicines that I can give them, and they want to try it...Like if they sound interested and they can't get them, then I can get the medicines for them...when I get them, I go to the reserve.

Family home visitors and staff in Indigenous-led programs in the city were able to meet the spiritual and cultural needs of infants and families and demonstrated a holistic approach to health promotion unique to the approach taken by providers in mainstream programs. This holistic approach was important for mothers wishing to connect with their Indigenous identity and supported their imparting these lessons on their infants.

**Family advocacy.** While both the mainstream and Indigenous-led programs advocated for families involved with child protection services, mothers described how providers in the Indigenous-led programs made this a priority. Many mothers were involved with child protection services (e.g. Children's Aid Society) and several were working tirelessly to regain custody of their children. The providers in Indigenous-led programs supported the family unit through their wrap-around and holistic approach to care, as well as specifically through advocacy with child protection services. One mother

shared how her Indigenous FHV went above and beyond, by supporting her at meetings with child protection services and fostering confidence in her ability to maintain custody of her son:

The native Healthy Babies worker, she has been working with me with CAS [Children's Aid Society] and that was my biggest challenge. Where I made sure he stayed in my care because I was dealing with addiction and then I was on methadone. But she has helped a lot. She has come to everything, like even if I called her and said "Okay, well they [child protection services] want to meet tomorrow at 11". She would drop everything and come...any questions I had, really she helped with, and just like everyday life. She has done a lot of referrals and stuff like that for me.

Another mother emphasized how the support she received from staff at the IFC was instrumental in helping her and her husband regain custody of their children:

They do help a lot. It is like they bring the family together and you do family things together and stuff like that. If you ever need help with anything, they help you...it is so amazing what these people can do for someone...they bent over backwards to help us try to get the kids back...they were coming to court, they were supporting us...I am so happy that I actually found this place.

Understanding the context in which the mothers and infants in their programs lived was key to informing the approach to family advocacy taken by Indigenous providers. One Indigenous FHV shared her perspective of how this approach was proving successful for Indigenous families in her care:

Budgeting and making sure they're confident when speaking to the [child protection services] worker. They're scared, and they feel like they have to do things... Like [child protection services] want you to go to parenting, they want you to go to mainstream. You can come to us. Like you can make those suggestions and I make sure those are followed through... [child protection services] says you need to do this, but don't give them any guidelines because [mothers] have no clue where to go. They don't even know who to call...it's basically setting them up to fail as well, right? Those are my goals...the success is more having their file closed from [child protection services], and there has been a lot more in the past two years than in my whole time here.

Mothers involved with child protection services found the support and advocacy of their Indigenous providers key to feeling confident as parents and empowered to meet the requirements of child protection services to keep their children in their care and their families intact. The contextual awareness demonstrated by Indigenous providers and the approach of Indigenous-led services facilitated their ability to provide holistic care which strengthened the family unit and set them up for success.

### **Discussion**

The results of this study contribute to a growing body of research on Indigenous early childhood health and well-being, and advance a new understanding of how urban-dwelling Indigenous mothers select and use health services to meet the health needs of their infants (A. Wright et al., 2018). Mothers involved in both mainstream and Indigenous-led services described how a comprehensive approach and the use of incentives and home visiting facilitated their access to services and promoted their engagement. Despite mothers' reports of excellent care by mainstream PHNs and FHV's, this study demonstrates that Indigenous-led programs are optimally positioned to promote access and use of early childhood health promotion services for Indigenous mothers and infants. Providers of Indigenous-led programs demonstrated this by recognizing the unique contextual factors influencing Indigenous mothers and infants and their socially responsive approach to care which included (a) building trusting relationships, (b) meeting social inequities, (c) recognizing and mitigating the impacts of historical, intergenerational and ongoing trauma—particularly through family advocacy, and (d) by providing for the holistic needs of families including cultural and spiritual needs.

Building trusting relationships between providers and mothers is pivotal to promoting engagement in early childhood health promotion services, especially when child protection services are involved (Gerlach et al., 2017). Despite this, providers struggle to build relationships with Indigenous mothers who commonly mistrust health providers for fear of child apprehension or other negative consequences if they were to be honest about their needs (Munns et al., 2016). In a study of Indigenous infant development programs in British Columbia, FHV's reported spending months to years to develop the level of trust necessary to engage parents in programs and effectively meet their needs (Gerlach et al., 2017). Similar findings were demonstrated in a study in Australia, where FHV's invested in building relationships before they could enter the home or engage in health promotion strategies (Munns et al., 2016). The providers from Indigenous-led programs in this study built long-term relationships with families, much longer than was typical in other mainstream services, which facilitated honesty, and led to their more effectively meeting the needs of families.

Indigenous-led programs met a range of social inequities through a wrap-around approach. Providing numerous services within the same IFC centre, including employment, addictions counselling, education, cultural events, family advocacy and others, has been promoted in the literature as a way to reduce inequities facing children and families (Gerlach et al., 2017, 2018; Moore et al., 2015). By contrast, caring for mothers and infants in siloed approaches causes additional stress for providers who find it difficult to facilitate change in the absence of integrated services (Munns et al., 2016). One poignant example of how Indigenous providers demonstrated contextual awareness

of their clients' social inequities was through their recognition of food insecurity. In response, FHV's and staff at the IFC prioritized supplying groceries and meals to families throughout their programming to meet this need.

Family advocacy was another extremely important way Indigenous providers demonstrated contextual awareness of the impact of colonization, the residential school system and the sixties scoop, with the resulting over-representation of Indigenous children involved with child protection services (The Truth and Reconciliation Commission of Canada, 2012). Understanding the impact of social inequity on one's ability to parent, Indigenous providers sought to keep families intact by addressing social inequities and advocating to child protection services for the inclusion of culturally appropriate interventions for their clients (The Truth and Reconciliation Commission of Canada, 2012). In a study in British Columbia, Indigenous providers used a similar approach to help parents to identify and work on their limitations to regain custody of their children (Gerlach et al., 2017). Likewise, the Indigenous-led programs in this study demonstrated a strengths-based and proactive approach to the support of families that provided them with opportunities to become successful parents.

Indigenous providers were better situated to meet the holistic health needs of Indigenous mothers and infants, which included the physical and mental/developmental as well as the emotional and spiritual needs of infants. This was a unique finding. In the broader study, mothers did not describe that this was offered by mainstream health providers or other health providers in primary and acute care settings (Wright, Jack, Ballantyne, Gabel, & Wahoush, Submitted October 15, 2018 to the International Journal

of Qualitative Studies on Health and Well-being; Wright, Jack, Ballantyne, Gabel, & Wahoush, Submitted October 15, 2018 to Qualitative Health Research).

In contrast, and as mentioned earlier, the exceptional ability and mandate of Indigenous-led programs to meet the spiritual health needs of infants may be what attracted mothers to use these specific services in the first place. Having Indigenous lived experience allowed an intimate knowledge of the meaning of traditional teachings, ceremonies, spirituality and culture as it relates to Indigenous people. Indigenous providers were able to thread these values and beliefs through their culturally relevant programming. Mothers described how Indigenous FHV's integrated traditional teaching and ceremonies in the home, by health teaching and making crafts, like beading and creating dreamcatchers and infant moccasins. Mothers also shared how traditional teaching that was incorporated into every class at the IFC, the availability of on-site Elders, and cultural events such as drumming and dancing were important ways to meet their own spiritual needs and those of their infants, particularly when such access was often difficult in an urban setting. Other reports in the literature suggest that facilitating cultural connections is important for those living in cities, where Indigenous families may experience spiritual and cultural disconnect through the impact of colonization, and where cultural connections can contribute to building confidence and self-esteem in children as they mature (Gerlach et al., 2018; Priest et al., 2012). Providers of Indigenous-led programming in Hamilton evidently understand this dilemma and work diligently to support the cultural and spiritual well-being of families.

The approach to care taken by providers of Indigenous-led programs is an excellent illustration of culturally safe and trauma and violence-informed care (TVIC). The foundation of culturally safe care, initially defined by Maori nurses in New Zealand, is an awareness of the differences that exist between people and of ensuring that caring for another is not negatively influenced by differing values and beliefs (Papps & Ramsden, 1996). When providing culturally safe care for Indigenous people, health providers require an understanding of the unique contextual factors that impact their health and well-being, including colonization, the residential school system, resulting trauma as well as other social inequities (The Truth and Reconciliation Commission of Canada, 2015). Indigenous-led services such as those in this study, are optimally positioned to provide culturally safe care for Indigenous people as Indigenous providers have lived experience and thus a visceral understanding of the impact of colonization and resulting systemic racism and structural trauma that affect their clients (The Truth and Reconciliation Commission of Canada, 2015). Providers taking a TVIC approach to care have an awareness of the potential of their clients experiencing further harm and/or trauma due to the influence of differing values and beliefs as well as policies and societal structures on their provision of care (Varcoe et al., 2016). Certainly, the mothers in this study confirmed the ability of their infants' providers from Indigenous-led programs to provide culturally safe and TVIC through an emphasis on building long-term trusting relationships, considering the context of their lives, promoting intact families and through providing holistic care that met their infant's spiritual health needs. As supported by findings in the literature, early childhood health promotion services for Indigenous infants



and children are most effective when they are developed and led by the Indigenous community itself (Smylie et al., 2016).

### **Implications**

The lessons learned from early childhood health promotion services, particularly those that are Indigenous-led, have important implications for practice, policy and future research.

**Practice.** First, health providers can provide culturally safe and TVIC by first reflecting on their own values and beliefs and how these may impact the care they provide to Indigenous mothers and infants (Papps & Ramsden, 1996; Varcoe et al., 2016). Demonstrating contextual awareness of social inequities, as well as the impact of colonization and resulting trauma on the lived experience of families is an important way to meet the unique needs of families. Building trusting relationships so that mothers feel comfortable sharing their struggles and needs also enables effective care. Providers in mainstream stream programs can acknowledge the importance of meeting the spiritual needs of infants, and link families with appropriate resources in the city to meet these needs. First, however, a better awareness of the availability of local Indigenous-led resources is necessary in Hamilton, which requires more effective partnering and information sharing with Indigenous organizations and services. Finally, PHNs can consider a dual approach to the care of mothers and infants by collaborating with Indigenous-led programs. For instance, PHNs and FHVs in the mainstream HBHC program can work together with FHVs from the Indigenous-led HBHC program to better meet the cultural and spiritual needs of Indigenous mothers and infants.

**Health policy.** Second, changes to policy at government and organizational levels are required to enable nursing practice changes. Through the Calls to Action from the Truth and Reconciliation Commission of Canada, all health providers should receive education on the history of Indigenous people, including the residential school system, sixties scoop and resulting trauma and social inequities facing many Indigenous people (The Truth and Reconciliation Commission of Canada, 2015). Cultural safety training is necessary for health providers to develop an awareness of the differences between themselves and those they care for, and to facilitate adjustments in care that are culturally relevant for Indigenous people. Additionally, training to provide TVIC is also important to make sure care does not result in further harm to those experiencing current or historical trauma. Government funding is needed to enable organizations to provide this training for their staff, and to support mainstream organizations so they can offer wrap-around care and build long-term relationships to meet the range of social inequities impacting the health of Indigenous mothers and infants. This shift in care from reactive to proactive is necessary to adequately address the health of Indigenous mothers and infants (Harrop, Urban Aboriginal Knowledge Network, & Atlantic Research Centre (UAKN Atlantic), 2017). Indigenous-led organizations such as the IFC, are best positioned to provide culturally safe care to Indigenous families, and thus also require adequate government support and funding to continue to meet the health needs of Indigenous families in urban settings. In particular, Indigenous-led programs require financial support to include Indigenous PHNs in their health promotion programs. Indigenous mothers and infants should be afforded the equal opportunity to benefit from the expertise of PHNs in

assessing the health and well-being of their infants as mothers in mainstream programs. Finally, culturally safe processes for identifying Indigenous families is necessary to link families with locally available culturally appropriate programming and services.

**Research.** Finally, future research is required to understand which health promotion interventions are best-suited to meet the health needs of Indigenous infants and their families as well as how to facilitate their access and use. In particular, how Indigenous infants with chronic health conditions access and use early childhood health promotion services remains unknown. Research is additionally needed to determine how to equip non-Indigenous providers so they too can appropriately care for Indigenous families in urban areas in culturally safe and trauma and violence-informed ways.

### **Limitations**

This study focused on the perceptions of mothers who accessed and used early childhood health promotion services to meet the health needs of their infants. The experiences of mothers who do not use early childhood health promotion services or who dropped out of programs were not elicited. These perspectives are important, however, to fully understand potential barriers to accessing this particular type of health care. In addition, it is necessary to acknowledge that the experiences of the mothers in this study may not reflect the experiences of all, and thus the reader should critically reflect on how applicable these results may be to their setting. Similarly, the experiences of fathers were not elicited in this study and may also have important implications on the access and use of early childhood health promotion services. Finally, the infants in this study were healthy and generally not experiencing chronic health conditions. Mothers of infants with

chronic health conditions, therefore, may experience different barriers to accessing and using early childhood health promotion services which require further exploration.

Although this study may not be all-encompassing – and was not intended to be fully representative – the results still clearly suggest strategies to improve and produce best results in health care access and delivery for Indigenous infants and their families.

### **Conclusions**

This study provided a unique opportunity to explore and determine the key characteristics of how Indigenous mothers experience accessing and using early childhood health promotion services to meet the health needs of their infants. Results suggest that holistic care, facilitated by a wrap-around approach and the building of long-term, trusting relationships is an important way to meet the numerous social inequities experienced by some Indigenous mothers and infants. Mainstream providers are encouraged to become trained in the provision of culturally safe and TVIC, especially as these approaches may offer important ways to support the access and use of health services by Indigenous infants and their families in other health care settings.

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Table 2

*Demographic Information: Participant Mothers*

<b>Variable</b>	<b>Category</b>	<b>Frequency (%)</b>
Age	<25 years	5 (26)
	26-30 years	8 (42)
	>31 years	6 (32)
Number of Children	First time moms	5 (26)
	2-5 children	14 (74)
Education	Less than High school	9 (47)
	Completed only high school	3 (16)
	Some College/University	7 (37)
Marital Status	Single/Separated	9 (47)
	Married/Common-law	10 (53)
Indigenous Identity	First Nations	15 (78)
	Métis	2 (11)
	Inuit	0 (0)
	Unknown Indigenous heritage	2 (11)
Income	Full-time Employment	7 (37)
	Ontario Works (social assistance)	10 (53)
	Disability Pension	2 (10)
Change of address during life of infant	Moved at least once	10 (53)
	Same residence	9 (47)
Regular Health Care Provider	Family physician	17 (90)
	Pediatrician	1 (5)
	None	1 (5)
Involvement with early childhood health promotion services	Mainstream (public) stream	3 (16)
	Early Years	1 (5)
	HBHC	3 (16)
	Indigenous stream	16 (84)
	Early Years	0 (0)
	HBHC	7 (37)
	IFC	12 (63)
	Both streams	3 (16)
	None	3 (16)

*Note.* N=19. Adapted from (Wright, Jack, Ballantyne, Gabel, & Wahoush, Submitted October 15, 2018 to the International Journal of Qualitative Studies on Health and Well-being).

Table 3

*Resulting Themes*

<b>Common Approaches</b>	<b>Unique to Indigenous-led Programs</b>
Comprehensive care	Wrap-around approach
Facilitating access through home visits	Building long-term trusting relationships
Promoting engagement in programming	Holistic care
	Family Advocacy

## **CHAPTER SIX**

### **Conclusions and Implications**

This research is the first in Canada to qualitatively explore how Indigenous mothers in urban areas select and use health care for their infants. It begins to address this gap in the literature, making important contributions to knowledge and nursing practice concerning the health and well-being of Indigenous infants and families.

This Chapter will summarize and discuss the key findings, beginning with those related to primary (Chapter 3) and acute care (Chapter 4), and finally early childhood health promotion services (Chapter 5). A discussion of the implications for nursing education, practice, health policy and research will then be described. Specific and more in-depth descriptions of the findings, together with the study's strengths and limitations, have also been discussed in each of the three previous Chapters (Chapters 3-5), each with their own extensive discussions related to primary care, acute care and early childhood health promotion services, respectively. The study strengths and limitations have also been discussed within each of these Chapters.

### **Summary of Findings**

The experiences elicited from participant mothers furthered our understanding of how they access and use primary care, acute care and early childhood health promotional supports to meet the health needs of their infants. Numerous barriers to primary and acute care were discovered and discussed (Chapters 3 and 4) including (a) living in disadvantaged neighbourhoods; (b) transportation barriers, particularly to attend the

children’s emergency department (ED) located across the city from where most participant mothers live; (c) financial barriers—fines for using walk-in clinics, expensive taxi fares and parking fees to attend the ED; (d) problematic wait times; (e) racist and discriminatory care; and (f) a lack of holistic care provision. In addition to these barriers to care, mothers also described factors that facilitated their access to primary and acute care services including (a) children’s specialization; (b) flexible appointments; (c) welcoming receptionists and clinic spaces; (d) alternative after-hours primary care options without financial penalties; (e) multi-service clinics with numerous health providers and services located in a central hub; (f) relationships with health providers; and (g) effective approaches to care (anticipatory guidance, collaborative, individualized, culturally-relevant & holistic). These factors are presented in Table 1: Summary of Findings. They provide valuable insight for health providers and organizations who, by addressing barriers and adjusting care provision, can improve access to services and promote positive health care experiences for Indigenous infants and their families.

Table 1

*Summary of Findings*

<b>Barriers to Primary &amp; Acute Care</b>	<b>Facilitating Access to Health Care</b>	<b>Indigenous Approach to Health Promotion</b>	<b>Theoretical Approaches that Promote Equitable Access to Health Care</b>
Disadvantaged neighbourhoods	Children’s specialization	Wrap-around approach	Culturally Safe Care
Transportation barriers	Flexible appointments	Long-term trusting relationships	Trauma & Violence-Informed Care (TVIC)
Financial barriers	Welcoming receptionists & clinic spaces	Holistic care that includes meeting spiritual & cultural needs	Family-Centred Care (FCC)
Problematic wait times	Alternative after-hours options to primary care	Family advocacy	
Racist and/or discriminatory care	Multi-service clinics		
A lack of holistic care	Trusting relationships Effective approaches to care		

Perhaps not surprisingly, but most remarkable, was that mothers’ experiences of using Indigenous-led early childhood health promotion services were more suited to their needs than mainstream early childhood health promotion services (Chapter 5). The effectiveness of Indigenous-led programs for meeting the health needs of Indigenous people and promoting positive health behaviours has been supported in the literature and

advocated for by the Calls to Action (items 4, 5, 21 and 23) of the Truth and Reconciliation Commission of Canada (TRC) (Durie, 2011; Liaw et al., 2011; Smylie et al., 2016; Teufel-Shone, Fitzgerald, Teufel-Shone, & Gamber, 2009; The Truth and Reconciliation Commission of Canada, 2015). See Table 2: Health-Related Calls to Action for a description of each Call to Action. Indigenous mothers of infants, however, had not previously identified Indigenous-led programs as most suitable to meeting their needs. Previously described in Chapter 5, Indigenous-led programs are self-governed, culturally relevant for their local Indigenous communities, and specialize in family violence and family advocacy (Ontario Ministry of Children Community and Social Services, 2018). Indigenous-led early childhood health promotion programs in this study optimized access and use of services by mothers through their unique approach to care. Indigenous providers demonstrated a deep understanding of the contextual factors distinctively impacting Indigenous mothers and infants in urban Hamilton. Surpassing the ability of mainstream services to provide comprehensive care; that is, caring for the unique needs of each family rather than using the same approach for all, Indigenous-led programs also took a wrap-around approach to health promotion. This wrap-around approach was essential to meeting the range of social determinants known to impact the health of Indigenous mothers and infants. They helped families secure affordable housing, providing culturally safe high school education for at-risk Indigenous teenagers in the city, provided employment counselling and education on a range of health issues, and many other issues. Mothers described how this preventative and proactive approach

to care met the holistic needs of their infants and families, contributed to their successful parenting and promoted intact families.

In addition to a wrap-around approach, Indigenous-led programs enabled longer-term trusting relationships, with much longer enrollment periods than is typical for mainstream programs. A family's enrollment in the Indigenous Healthy Babies Healthy Children (HBHC) program continued so long as at least one child in the family was under the age of six years. This meant some families were enrolled in the program for a decade or longer. In contrast, a child's eligibility for enrollment in the mainstream HBHC program (up until the age of six years) did not match their typical length of enrollment—usually one year or less. Programs offered at the Indigenous Friendship Centre (IFC) addressed the needs of all ages, providing opportunities for members to grow together and to build strong and long-term relationships with providers and with each other.

A particularly important observation (described in Chapter 5) was the ability of Indigenous providers and Indigenous-led programming to meet the spiritual and cultural health needs of Indigenous infants and their families. Mothers expressed how health providers in mainstream areas of health care (primary care, acute care, and early childhood health promotion services) did not always address their infant's spiritual or cultural needs. Indigenous providers were ideally situated to provide for the spiritual and cultural needs of infants and their families, as they understood the traditions and beliefs of families, and if unsure, asked mothers how they could best meet their needs. Indigenous providers incorporated traditional teachings into their health promotion education and engaged in traditional crafts with mothers and infants to facilitate health education and



infant learning. Indigenous providers also had access to traditional medicine, otherwise difficult to obtain in urban Hamilton, which they supplied to many of the mothers in this study, so that they too could participate in ceremony. Lastly, the IFC in Hamilton strives to provide the urban Indigenous community with access to Elders and other knowledge holders, as well as opportunities to participate in other ceremonies and cultural events. This access was extremely important to mothers who wanted their children to be exposed to their culture to support building their Indigenous identities.

Finally, Indigenous providers prioritized family advocacy and care of Indigenous mothers and infants throughout their programs. Understanding the historical and ongoing trauma in the lives of their clients, Indigenous providers employed sensitive and strength-based approaches. They promoted intact families and advocated on their behalf with child protection services. Many mothers reported how the wrap-around approach of Indigenous-led programs helped them meet the requirements set by child protection services to maintain or regain custody of their children. Indigenous providers were familiar with the legal rights of Indigenous families and worked diligently to ensure their clients were given the opportunity to engage in Indigenous-led programs to meet these rather than in mainstream programs where Indigenous history, traditions and values were not consistently understood.

Indigenous mothers in this study favoured the use of Indigenous-led early childhood health promotion programs because they promoted positive parenting, healthy growth and development of infants and also helped them maintain intact families. The approaches of these programs demonstrated their application of two important models of

care: culturally safe care and trauma and violence-informed care (TVIC). While Indigenous providers are most ideally situated to care for the health of Indigenous mothers and infants, non-Indigenous providers in mainstream health care can better meet the needs of Indigenous mothers and infants through enacting these approaches to care. The implications for nursing practice are the most important contributions to the literature of this research and to supporting the health of Indigenous infants and families. These implications are described next.

### **Alignment of the Findings With the TRC**

The findings from this study align with the health-related Calls to Action from the TRC of Canada. The TRC was established in 2008 to investigate the impact of the residential school system on the health and well-being of Indigenous people in Canada (Truth and Reconciliation Commission of Canada, 2018). Through the creation of an accurate historical record of the residential school legacy, Indigenous people were given the opportunity to engage in and contribute to reconciliation with the government of Canada (Truth and Reconciliation Commission of Canada, 2018). The TRC resulted in 94 Calls to Action, urging the government to acknowledge and address the trauma inflicted by the residential school system and the resulting inequities experienced by many Indigenous people in Canada (The Truth and Reconciliation Commission of Canada, 2015). The Calls to Action that relate specifically to health consist of recommendations 18-24 and 55, and those concerning child protection services (items 4 and 5) are also applicable to Indigenous mothers and infants. See Table 2: Health-Related

Calls to Action, for a brief synopsis of these recommendations. The implications of this research will next be described in terms of their alignment with these Calls to Action.

Table 2

*Health-Related Calls to Action*

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<b>Calls to Action</b>	
4	Federal government to enact Indigenous child-welfare legislation that provides national standards for apprehension and care including the right for Indigenous government to (a) create and establish their own agencies; (b) recognition of the residential school system in welfare agencies and court systems; and (c) place Indigenous children into culturally appropriate care.
5	Development of culturally appropriate parenting programs
18	Recognition of the current state of health for Indigenous people as a direct result of colonization and health policy.
19	Close the gap in health outcomes between Indigenous and non-Indigenous people.
20	End jurisdictional disputes to funding health initiatives for off-reserve Indigenous people including First Nations, Métis and Inuit.
21	Government funding of Aboriginal healing centres to holistically care for the harms inflicted by residential schools.
22	Recognize Indigenous traditions and therapies (including Elders and traditional healers) within the health system and incorporate them into the mainstream health.
23	Increase the number and retention of Indigenous health professionals, and for all health professionals to complete cultural competency training.
24	Require all students in health disciplines to become educated on the history of Indigenous history, and “skills-based training in intercultural competency, conflict resolution, human rights and anti-racism” (The Truth and Reconciliation Commission of Canada, 2015, p. 212).
55	Government annual reports outlining progress concerning closing the gap of health outcomes between Indigenous and non-Indigenous people.

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*Note.* Adapted from The Truth and Reconciliation Commission of Canada, 2015

## **Implications**

The following describes the implications that result from this research, and relate to the areas of nursing education, nursing practice, health policy and future nursing research. The alignment of these implications with the Calls to Action of the TRC is noted within the discussion.

### **Implications for Nursing Education**

To provide culturally safe and TVIC, health professionals first require a thorough understanding of the history of Indigenous people in Canada. Colonization and the subsequent forced assimilation of Indigenous people through the residential school system and Sixties Scoop are contextual factors uniquely impacting the health and well-being of Indigenous people (The Truth and Reconciliation Commission of Canada, 2015). Understanding the contribution of these factors to ongoing, historical and intergenerational trauma experienced by many Indigenous mothers and infants is imperative to providing care that is equitable, culturally safe, free from harm and trauma, and required to meet the Calls to Action (items 18, 22 and 23) (Papps & Ramsden, 1996; The Truth and Reconciliation Commission of Canada, 2015; Varcoe et al., 2016). Health care organizations and colleges and universities can accomplish this and meet the Calls to Action (items 23 and 24), by providing cultural safety training first to members of leadership, management and nursing faculty who can then support existing nurses and nursing students in learning these concepts. Once leaders and educators have this appreciation and understanding, curriculum can be developed to provide the tools and resources necessary to support the education of existing nurses and nursing students in a culturally safe teaching and learning environment (The Truth and Reconciliation

Commission of Canada, 2015). Health care organizations can ensure staff receive accurate education on the history of Indigenous people. They can also facilitate interaction with local Indigenous Elders and knowledge keepers to provide nurses with education on how best to meet the needs of the local Indigenous community. This enables nursing students to be provided with locally-relevant context and education of local Indigenous traditions, customs and beliefs to promote equitable health care access and responsive approaches to care. Entry-level nursing programs at colleges and universities can offer nursing studies a strong foundation in Indigenous history, and then continue to thread these lessons along with cultural safety principles throughout the programs. Nursing students can practice interacting with Indigenous patients and their families through simulation, building their skills to provide culturally safe care by recognizing and responding to the potential power imbalances present in a nurse-client relationship.

In addition, institutions can engage staff and students in the numerous cultural safety programs that are currently available in Canada, with many available online (Churchill et al., 2017; Provincial Health Services Authority British Columbia, 2018; Southwest Ontario Aboriginal Health Access Centre, 2018). The implementation of these programs is still relatively new, and further work to evaluate their effectiveness is required (Churchill et al., 2017). In a recent report, Churchill et al. (2017) suggest cultural safety programs need to focus on power, privilege and equity through using anti-racism pedagogy and transformative learning theory to promote shifting students' beliefs and values and challenge resistance to change.

While cultural safety training is imperative to promote equity for Indigenous people, health care organizations and educational institutions can further support nurses caring for Indigenous people by providing additional training on TVIC and the importance of holistic care within a Family Centred Care (FCC) approach. An understanding of TVIC encourages nurses to critically assess how existing policies and nursing care may perpetuate further harm, and provides them with support to develop an awareness of the potential for trauma and violence in the lives of their patients, as well as how this exposure to trauma impacts health outcomes (Varcoe et al., 2016). In this study, training and expertise in FCC was also identified as an important way for nurses to meet the needs of Indigenous mothers and children; by providing holistic care, respecting the role of mothers and prioritizing effective communication and collaborative decision-making with them in the care of their infants' health (Harrison, 2010). Existing cultural safety programs like those described above, provide an excellent educational opportunity for existing nurses on the application of TVIC and FCC principles within the context of caring for the health of Indigenous people. These programs can help nurses gain an understanding of these approaches, and learn how to apply this knowledge to their practice. Cultural safety, TVIC and FCC principles should be introduced in the first year of nursing programs in a college and/or university context, and be built on throughout the remainder of the degree to allow nursing students the opportunity to apply these concepts in their clinical placements and to grow their knowledge and skills.

### **Implications for Nursing Practice**

Once they understand the impact of contextual factors and potential sources of trauma, findings suggest that nurses can better meet the needs of Indigenous mothers and infants. Changes to nursing practice can improve access and promote positive health care interactions, all of which have positive implications for the health and well-being of Indigenous families. As discussed, nurses can gain an understanding of culturally safe, TVIC and FCC approaches to care by engaging in training and education. Next, nurses should develop self-awareness, through examining their own values and beliefs and how these differ and may impact others. Nurses can better meet the needs of Indigenous mothers and infants once they understand the impact of contextual factors and potential sources of trauma on the health and well-being of Indigenous families.

**Transformative learning theory.** The adoption of research evidence into nursing practice often requires a shift in nurses' preconceived attitudes and beliefs held by nursing staff. Without this adaptation, research evidence is commonly underutilized in clinical practice (Matthew-Maich, Ploeg, Jack, & Dobbins, 2010). The application of transformative learning theory to the development of educational tools and resources can help nurses make the link between research evidence and their practice, which may lead to sustained practice change (Matthew-Maich et al., 2010). Transformative learning theory, developed by Mezirow, is a type of adult learning theory that recognizes the need for adult learners to understand how actions are linked to knowledge and beliefs (Mezirow, 1991). An initial disorienting dilemma is commonly uncomfortable for learners, but necessary to promote the unlearning of preconceived notions and to allow

for the relearning of a new perspective (Matthew-Maich et al., 2010). For example, when first learning about the residential school legacy, nurses may be uncomfortable to hear of the abuse children suffered at the hands of educators. This initial shock, however, challenges nurses to unlearn negative stereotypes associated with Indigenous people and coping behaviours (such as substance use). Nurses can then relearn a new perspective of understanding that Indigenous people may choose certain coping behaviours to deal with the harm and trauma they experienced in residential schools. Critical reflection (reflection on one's values, beliefs and position in society) and critical discourse (discussion of one's ideas and beliefs with others to reach mutual understanding) are also essential components of transformative learning theory that contribute to altering perspectives and creating lasting change (Matthew-Maich et al., 2010). Transformative learning theory has been extensively studied and used across numerous disciplines since its inception in the late 1970s, and its components and their definitions continue to be useful in promoting adult learning (Taylor, 2007).

Cultural safety training programs require learners to challenge their preconceived attitudes and beliefs before new knowledge and learning can be applied to clinical practice. These types of programs are more effective when transformative learning theory has been applied in their development (Churchill et al., 2017). The application of transformative learning theory to educational programs, tools and resources that focuses on cultural safety, TVIC and FCC is an important way to effectively promote the use of research evidence in clinical practice. Strategies specific to each of these approaches to care will now be individually explored.



**Culturally safe care.** An important aspect of providing culturally safe care is the provision of holistic care, which includes meeting the physical, mental, emotional and spiritual needs of Indigenous mothers and infants. While not every nurse can personally address the spiritual health needs of Indigenous infants, they can support families to meet those needs. In order to do so, nurses require an understanding of the important role of traditional medicine and ceremonies in the health and wellness of Indigenous people (Call to Action item 22). Nurses can also strive to provide holistic care by recognizing how spiritual health needs are of equal importance to physical, mental and emotional health needs. Individual values and beliefs differ between First Nations, Métis and Inuit people, so it is important that nurses ask each person how to best support their health. Online resources are available to health organizations and can help nurses apply these new learnings to their nursing practice. By pushing for their institutions to partner with local Elders, knowledge holders and Indigenous organizations, staff can also learn about the different beliefs and values common to their local Indigenous communities.

Nurses can be strong advocates for the system and policy level changes that are required to support the spiritual needs of Indigenous families. In some settings, such as the fast-paced environment of acute care, staff may find meeting the spiritual needs of mothers and infants more difficult because their patient interactions are short. Yet mothers in this study wanted staff to ask about their spiritual well-being and direct them to on-site chapels and quiet areas where they could engage in ceremony. Institutions could instigate the development, for example, of policies that allow for on-site smudging, the burning of traditional medicines, and enabling Elders to be available on-site for

families in need. If policies already exist, nurses can prioritize familiarizing themselves with these policies, so they are prepared to offer Indigenous families with these options.

Finally, this study highlighted how Indigenous people living off-reserve in urban Hamilton have difficulty obtaining traditional medicines and accessing cultural events. Nurses can familiarize themselves with locally available cultural resources for Indigenous families as well as insist their organizations make this information more widely known to families. Nurses and other health professionals will then be better equipped to link Indigenous mothers and infants with these supports.

**TVIC within a culturally safe approach.** Providers should emphasize the use of TVIC principles within a culturally safe approach when caring for Indigenous mothers and infants. While TVIC principles are extremely important to consider and employ, they become embedded within a cultural safety lens when caring for Indigenous families. This emphasizes the importance of culture—rather than trauma and violence—to the health and well-being of Indigenous people. Culture plays an important contextual role in the lives of Indigenous people, as Indigeneity itself was the target of colonization, that left a legacy of trauma and harm through the residential school system, the Sixties Scoop and racist policies that continue to disproportionately disadvantage and impact the health of Indigenous people (Papps & Ramsden, 1996). Nurses should therefore first appreciate how culture provides the overarching context in which experiences of trauma and violence are more likely to occur. They can then promote cultural safety through enacting TVIC principles of care, by (a) ensuring safe places for health interactions to occur; (b) understanding the association between coping behaviours, such as substance use and

trauma and violence; (c) creating welcoming health care settings; and (d) engaging in effective communication to avoid further harm (EQUIP Health Care, 2017). The mothers in this study described examples of racism and discriminatory care that made them feel unwelcome in health care settings and stressed a desire for their infants to grow up feeling accepted in the health care system. The application of TVIC is an important way to help mitigate these negative encounters and to promote positive exchanges for Indigenous families.

Additionally, nurses should demonstrate contextual awareness and attention to trauma when dealing with child protection services issues with Indigenous families (Call to Action item 4). As discussed in Chapter 3, colonization and subsequent racist policies have led to the over-representation of Indigenous children involved with child protection services, and has resulted in social inequities that impact parenting for some families (The Truth and Reconciliation Commission of Canada, 2015). Coupled with experiences of the residential school system and the Sixties Scoop, Indigenous people are extremely likely to face recurring trauma and harm if the involvement of child protection services is not dealt with in culturally safe and TVIC ways. Nurses informed by cultural safety and TVIC understand that threatening the involvement of child protection services as a punitive action for missed appointments has the potential for devastating consequences; perpetuating feelings of trauma and resulting in fear of health providers that may lead to negative health outcomes. Instead, nurses can support families involved with child protection services by (a) promoting effective communication between child service workers, children and their parents; (b) encouraging the involvement of an Indigenous

child welfare advocate; (c) promoting parental engagement with culturally-appropriate parenting programs and mother-infant services to reach goals mutually set by mothers and child service workers; and (d) advocating for the self-determination of Indigenous communities to create and establish their own child welfare agencies to provide Indigenous children with culturally safe services and placements (The Truth and Reconciliation Commission of Canada, 2015). Applying TVIC principles within a culturally safe lens is an important way to effectively and sensitively meet the health needs of Indigenous infants and their families.

**Family-centred care.** Mothers in this study shared ways in which primary care providers facilitated their access to health care and promoted positive health care interactions by incorporating FCC principles. A FCC approach to caring for mothers and infants includes the following principles: (a) promoting early mother-infant attachment; (b) using a holistic approach; (c) applying culturally appropriate care; (d) recognizing the distinct needs of Indigenous families; (e) collaborating with mothers in decision making; (f) and using an evidence-based approach that is constantly under evaluation (Public Health Agency of Canada, 2017). While FCC is well described in the literature and widely embraced and applied by nurses across Canada, the best provision of culturally appropriate and holistic care within an FCC approach is not well understood (Dennis et al., 2017; Shields, 2015). The findings of this study, however, contributes to this gap in the literature, with mothers describing how nurses could meet their needs and the needs of their infants in ways that are aligned with FCC principles.

As described previously, nurses can better meet the cultural and spiritual needs of their infants by understanding and acknowledging the important contribution of these health needs to the overall health and well-being of Indigenous people. Linking families with cultural and spiritual resources within health care institutions and within the city, is another way that nurses can facilitate meeting these needs.

Mothers also valued nurses who recognized the important role of family in promoting and maintaining the health of infants, and who partnered with them as experts of their infants' health. Mothers felt cared for when nurses used effective communication, with active listening, validating mothers' opinions and concerns, and engaging in collaborative decision-making with mothers to promote healthy infant growth and development.

Building a trusting relationship between mothers, infants and health providers was expressed as important because it facilitated communication, made mothers comfortable to share their needs and concerns, and infants were more at ease with familiar health providers. Consistency of health providers in primary care settings were key in building relationships, as mothers and infants had numerous opportunities to build trust during multiple health care encounters. Nurses can promote consistency in their own practice by assigning families to see the same nurse for each health care encounter, or by promoting similar policies in their organizations and institutions. This study contributes important recommendations that can help nurses, already experts at providing FCC, in better meeting the specific needs of Indigenous infants and their families.

The findings of this research suggest important strategies for nursing practice to promote equitable access to health care and promote positive interactions with health providers. Specific ways to enact culturally safe, TVIC and FCC approaches to care with Indigenous mothers and infants in urban areas have been described and explored. The application of transformative learning theory to educational initiatives has been identified as an important way to promote the translation of research evidence to nursing practice. Nurses maintain an ethical obligation to do their utmost to promote equitable health care and health outcomes (Thorne et al., 2015), and as they represent almost half of the entire health care workforce in Ontario, they are most appropriate and capable of making positive impacts in the health and well-being of Indigenous infants and their families (Registered Nurses Association of Ontario (RNAO), 2017). The strategies outlined here are effective ways for those meaningful impacts to be made.

### **Implications for Health Policy**

**Organizational.** Organizational support is required to provide the space necessary for changes in nursing practice to take place. First, organizational policy is needed for cultural safety training for staff and students, as mandated through the TRC. Second, policies supporting partnerships between health providers and Indigenous community members (Call to Action item number 22), are necessary for nurses to learn about local customs, traditions, values and beliefs, and to help provide the provision of culturally safe and holistic care for Indigenous families. Third, organizations should develop ways to support Indigenous families wishing to participate in ceremony (such as smudging) and to recognize the importance of traditional medicine to health and wellness, promoting its

inclusion in the health care system (Call to Action item 22). Finally, organizations can more effectively promote health and wellness by meeting a range of social needs through a service model that incorporates a wrap-around approach. This type of service model, however, first requires government support and adequate funding.

**Government.** For changes to nursing education, practice and organizational policies to occur, government must first adopt the TRC's Calls to Action as necessary mandates to facilitate much-needed change. Doing so on a national level then requires organizations and institutions to adopt the recommendations as well, and for staff to do likewise. Following government-level adoption of the Calls to Action, sufficient funding investment is then needed to adequately support organizations and institutions for the enactment of the recommendations.

***Cultural safety training.*** Providing nurses with access to accurate and effective cultural safety training (Calls to Action items 18 and 23) also requires government funding. This is necessary so that recommendations can be adequately addressed, and to adequately compensate members of the Indigenous community for partnering with organizations and institutions in enacting the Calls to Action. The development of culturally safe programs and services in urban areas— including Indigenous-led programs that support Indigenous language development and early childhood services—also requires government support and financial backing (Call to Action item 5) (The Truth and Reconciliation Commission of Canada, 2015).

***Self-determination of Indigenous Communities.*** Adequate financial support for Indigenous-led programming such as the Indigenous-led HBHC and IFC programs in

Hamilton, is essential to facilitate their wrap-around approach that meets a wide range of needs in culturally safe ways— promoting successful parenting, intact families and setting infants on a life course for health and well-being. Indigenous-led programs are best situated to care for the health of Indigenous mothers and infants, as their culturally relevant programs align with the beliefs and values of the Indigenous families they serve (Smylie et al., 2016). Government legislation is necessary to support the self-determination of Indigenous communities and enable their ability to continue to develop and provide Indigenous-led programs that care for the health of the local Indigenous community (Call to Action items 20 and 21).

*Health equity for Indigenous-led programs.* The inequity experienced by Indigenous mothers and infants was clearly demonstrated by the absence of a nurse in both the Indigenous-led HBHC and IFC programs. Individuals accessing mainstream programs do have access to nurses, yet inadequate funding for Indigenous-led programs has resulted in a lack of integrated health providers. Government policy is required to support the important and valuable contribution made by nurses to infant health and well-being within Indigenous-led programs. For example, nurses can engage in health education, and conduct validated assessments of infant growth and development that lead to early detection of delay or concerns. They can provide nursing intervention in evidence-informed ways, and refer to other health providers and services as required (College of Nurses of Ontario (CNO), 2014). In particular, the recruitment of Indigenous nurses to these programs is imperative, as they are best able to care for the health of



Indigenous people, yet are currently underrepresented in the nursing profession (Call to Action item 23) (The Truth and Reconciliation Commission of Canada, 2015).

***Traditional medicine.*** By adopting the recommendations of the TRC, the government acknowledges the urgent need for culturally safe care across the health care system, and, as such, policy is required to promote the inclusion of traditional medicine within mainstream health care. Many traditional medicines remain largely unknown to non-Indigenous people. Given a long history of misappropriation and lack of remuneration when traditional knowledge has been shared and profited from, Indigenous people are hesitant to share these therapies (Simeone, 2014). As a result, many traditional medicines have not been empirically tested, and they lack Western standards of evidence to support their use (Simeone, 2014). Legislation is therefore required to protect from legal consequences those who provide and receive traditional medicine (Call to Action item 22). For example, government policy would ensure legal actions against Indigenous families who use traditional medicine in place of, or in conjunction, with Western treatments for childhood cancers would no longer occur (Brean, 2015). Partnerships with Indigenous Elders, knowledge keepers and healers are necessary to effectively integrate traditional medicine into mainstream health care.

***Research funding.*** Finally, the support of research initiatives that aim to improve the health of Indigenous people in Canada requires a commitment of government funding (Call to Action item 19). As the health recommendations of the TRC are broad and far-reaching, it is essential that research measures impact and outcomes to further the

appropriate allocation of funding to initiatives that prove most effective for Indigenous people.

### **Next Steps for Nursing Research**

The findings of this research make important contributions to the literature by providing strategies to improve health care delivery for Indigenous infants and families in a range of health care settings. There are several areas for nursing research that are imperative in order to continue the trajectory of promoting health equity and improved health outcomes for Indigenous infants and their families (Call to Action item 19) (The Truth and Reconciliation Commission of Canada, 2015). These areas include nursing research pertaining to (a) the health of Indigenous infants and the role of parents in supporting their infants' health and well-being; (b) health services research with a focus on the role of health providers and health interventions; (c) global collaborations; and (d) the application of the Two-Eyed Seeing framework and other Indigenous methods to research with Indigenous people in Canada. These areas will now be further explored.

**Research and the health of Indigenous infants.** Smylie et al. (2011) have undertaken vitally important epidemiological studies to examine the health needs of First Nations people in Hamilton, Ontario. However, there remains a paucity of accurate data reflecting the health of Indigenous infants in Canada, particularly relating to those living in urban areas, and specifically detailing the health of First Nations, Métis and Inuit infants. Data relating to the health of children have been aggregated, and little is known about the health of Indigenous infants and how best to provide health care to meet their needs. Thus numerous areas for future research are needed to specifically detail the health

needs of Indigenous children in infancy and across the lifespan which is urgently required if health providers are to adequately address the health needs of these infants and their families.

In addition, further investigation would accurately depict the health of Indigenous people living in urban and other areas and provinces in Canada. Such data should consist of birth indicators, including rates of preterm birth, birth weights, rates of birth injury as well as associated maternal health conditions. These data would provide nurse researchers with evidence of whether further research was required, and which areas of maternal and newborn health should be prioritized. Similarly, infant health indicators such as neonatal and infant mortality rates, early childhood illnesses leading to hospital admissions, and vaccination rates—specifically for urban-dwelling First Nations, Métis and Inuit groups— would enable better planning of early childhood health promotion for infants of specific Indigenous groups. Quantitative data pertaining to parental use and access of health services for infants would also help in the understanding of service gaps and to determine whether interventions improve outcomes. These types of accurate data are needed if we are to recognize when health interventions are successful and health outcomes begin to improve for Indigenous infants and their families (Calls to Action items 19 and 55).

Very little is known about the effectiveness of health interventions for improving Indigenous infant health outcomes. Through partnering with urban Indigenous organizations and services, mixed-method approaches to research can be used to develop culturally-relevant interventions which can then be evaluated to determine how and why

their effectiveness meet the health needs of Indigenous infants and families. For example, a mixed methods study examining the health outcomes of infants in the Indigenous-led HBHC program (e.g. by measuring school readiness) and the engagement of mothers in the program, may provide convincing evidence to increase government financial support to Indigenous-led programs.

It is important to know how mothers of infants with chronic health conditions access and use specialty services, so that their access and use can be improved. Similarly, future research can further our understanding of how the accessibility and delivery of early childhood health promotion services can be enhanced to better meet the needs of Indigenous infants with chronic conditions. Findings from this study relate primarily to how these programs and services promote access and use by mothers of infants who had used early childhood health promotion services. Therefore, more research is required to identify mothers who do not use these programs and to identify what the potential and prohibitive barriers to services are.

Finally, this study excluded fathers, and focused solely on the experiences of mothers because they are primarily responsible for maintaining the health of their infant, and are more likely to head single parent families (Smylie & Adomako, 2009). Future research should endeavor to understand how fathers experience selecting and using health care for their infants in order to more holistically promote access and use of health services.

**Health services research.** Further study of health providers and health services is necessary to better address the access and use of health services by Indigenous mothers

and infants. First, understanding how nurses and other health providers experience and perceive caring for Indigenous people can inform the design of interventions and tools health providers use to support their provision of culturally safe care, TVIC and FCC. Knowledge translation strategies disseminating the findings of this research would be greatly enhanced through a more thorough understanding of how health providers perceive their ability to care for Indigenous families. Future research on how the unique wrap-around strategy used by Indigenous-led programs impacts the health outcomes of Indigenous mothers and infants is important to enable advocating for adequate government funding that supports the self-determination of Indigenous communities. These types of health service research are necessary to fulfill the TRC's Calls to Action that require translation of culturally safe care training into practice in effective and impactful ways.

**Global collaborations for research.** The United States, Australia and New Zealand have undergone a similar period of colonization, and Indigenous people in these countries experience comparable inequities to Indigenous people in Canada. International collaborations in future nursing research endeavors offers opportunities to apply effectively to the Canadian context, interventions and strategies implemented for Indigenous infants and families from other countries. Cultural safety, for example, was developed by Maori nurses in New Zealand, and as a result, nursing researchers have embarked on additional research to address its application and use there, and in Canada. These global partnerships hold great potential to make meaningful and effective impacts for Indigenous people here and may offer reciprocal exchanges.

**Two-Eyed Seeing approach.** As demonstrated in Appendix B: Two-Eyed Seeing integrative review, the description and application of Two-Eyed Seeing to research requires further development. Because it is a relatively new approach to studies with Indigenous people, researchers inconsistently characterize and apply its components. Details pertaining to data analysis and knowledge translation vary significantly and require further exploration. For example, in this study, collaborative data analysis weaved together both Western and Indigenous worldviews, as described by Bartlett, Marshall & Marshall (2007). This was not well explained, however, by the developers of Two-Eyed Seeing. In future, as researchers contribute to the literature by describing their application of the framework to data analysis, we will be better equipped to apply the framework going forward. Future publications of Appendix B: Two-Eyed Seeing integrative review, will contribute to its more consistent interpretation in the literature and its application to future research. Finally, this study applied Two-Eyed Seeing throughout the research process. This collaborative approach with the Indigenous community was valued and necessary to build relationships with community members and participants, and to conduct the research ethically. A similar approach will be taken in future research.

**Knowledge translation.** The findings of this study have important implications to promote equitable access to health services and to potentially contribute to improving health outcomes for Indigenous infants and their families. As such, appropriate knowledge translation strategies are essential to share these implications with key stakeholders and clinicians. The findings have been presented to clinicians and researchers at numerous academic and health-related conferences through poster and oral

presentations, and similar foundational work was published along with Chapter 2 in academic journals (A. Wright et al., 2016, 2018). Results as described in Chapters 3-5 will each be published to further disseminate the findings to clinicians and researchers on a national and global scale and will also be shared with clinicians in Hamilton (nurses, nurse practitioners and physicians) through in-person presentations at health care institutions. Collaboration with nursing organizations (the Canadian Indigenous Nurses Association and the Canadian Association of Neonatal Nurses), who advocate for and promote best practices for nurses and health care nationally will facilitate the sharing of the findings to members of government and leaders in health care. (The researcher is a member of the Board of Directors for both organizations).

Other knowledge translation strategies will be developed by the Indigenous community in Hamilton (specifically staff at the IFC), and enacted and promoted collaboratively with the researcher. One suggestion made by a mother participant was to develop a short video of mothers sharing their experiences and their suggestions for change. This video would be a valuable learning tool for clinicians and made accessible to health providers within Hamilton's hospitals and primary care clinics. Its success would be measured by how many times it was viewed via an online platform, and linked to an online survey to quantitatively measure user satisfaction. It also holds the potential for transformative change. If deemed successful, the video could be distributed across Ontario, as well as nationally and used as an educational resource for students in health-related fields within colleges and universities. Funding for such a venture will be sought

collaboratively by the Indigenous community and the researcher, if the community pursues this strategy, or something similar.

The findings of this study have important implications that span a broad number of nursing-related areas, including nursing education, nursing practice, health policy and nursing research. These implications align with the Calls to Action of the TRC, further validating their necessary application to meet the needs of Indigenous mothers and infants in urban communities. As mentioned earlier, nurses are uniquely well-positioned to make meaningful changes to health service delivery as they represent the largest component of the health care workforce in Ontario and share ethical imperatives to improve the health and well-being of their patients and clients.

### **Conclusions**

This research represents the first qualitative study to address how Indigenous mothers living in urban areas select and use health care services to meet the health needs of their infants. The findings are specific to the health of Indigenous infants and not previously articulated in the literature. Additionally, the urban setting provides important contributions to our previously limited understanding of the health of urban-dwelling Indigenous infants. Important strategies have been identified that could enable nurses and health providers to improve access to health care and promote positive health care interactions for Indigenous mothers and infants in a range of settings, including primary and acute care, and early childhood health promotion services. These recommendations align with the Calls to Action made by the TRC, further validating the importance of their application to the provision of health care in urban settings for Indigenous infants and



families. Most remarkably, implications resulting from this study primarily apply to nursing practice. Nurses, therefore, should feel empowered to apply culturally safe, TVIC and FCC principles to their own practice, resulting in immediate and positive impacts promoting access to health care and positive health care experiences, which may improve the health outcomes of Indigenous infants and their families.

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## APPENDICES

### Appendix A: Operational Definitions

<b>Term</b>	<b>Definition</b>
<b>Access</b>	Access to health care is complex and does not merely refer to one's ability to engage the health care system to meet a health need. Andersen's model (1995) accounts for the variables that influence access.
<b>Acute Care Services</b>	Secondary level of care for urgent or life-threatening ailments. May be accessed for primary care when primary care is unavailable.
<b>Colonialism</b>	A nation's control of another country, territory or people (Czyzewski, 2011). Colonialism occurred in Canada in the late 1700s with the settling of Indigenous lands by the Europeans and forced assimilation to European culture, religion and lifestyle.
<b>Cultural Relevancy</b>	Care that is meaningful to the individual and their unique cultural context.
<b>Cultural Safety</b>	Determined by the recipient as safe care, in which they are respected and collaborated with. It is not consistent between individuals.
<b>Dyad Unit</b>	A mother and her infant are considered a dyad unit, as the mother interacts with her infant to determine his or her needs, and the infant is dependent on the mother for having his or her needs met.
<b>Early Childhood Health Promotion Services</b>	Early childhood health promotion services include programs and services for parents of infants and young children that facilitate healthy parent-infant attachment and healthy growth and development of infants
<b>Elder</b>	An Elder is defined as an Indigenous person who has been given authority by his or her community as a sacred knowledge holder, with a vast knowledge of their culture and tradition, often speaking their traditional language, and knowledgeable in traditional medicine.
<b>Health Services</b>	Health services include primary care, acute care, specialty services and early childhood health promotion services.
<b>Indigenous</b>	Indigenous refers to peoples originally residing in Canada prior to colonialism by the Europeans. Indigenous peoples in Canada include

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	First Nations, Inuit and Métis peoples. Although referred to collectively as Indigenous, not all Indigenous people share the same cultural values and beliefs.
<b>Indigenous Community</b>	A collective group of Indigenous peoples. A community can refer to a territory, organization or community of interest.
<b>Indigenous-led</b>	Programs are considered Indigenous-led as they operate under their own organizational mandates and policies and provide culturally relevant programs for their local Indigenous community.
<b>Infant</b>	Refers to children less than 24 months of age. The age range of 0 to 24 months has been used to allow for adequate engagement with the health care system for health promotion activities and illness and disease management.
<b>Knowledge Holder</b>	A knowledge holder is recognized by their local Indigenous community to possess a significant amount of Indigenous knowledge (which may pertain to traditions, ceremonies, teachings, traditional medicine, etc.). An Elder is considered a knowledge holder, but a knowledge holder may not be held at the same esteem as an Elder.
<b>Mother</b>	Any self-identifying Indigenous woman who declares herself a mother.
<b>Primary Care</b>	Routine health care (including well-baby checks, growth and development, immunizations and for treatment of mild illness or injury).
<b>Select</b>	When an individual selects a health service for use, they can be said to be choosing from all the health services known to be available to them, to the best of their knowledge and abilities, and according to their preferences.
<b>Urban</b>	Urban areas are defined as per Statistics Canada (Statistics Canada, 2011), as areas with a population of greater than 1,000 people, and a density of at least 400 people per square kilometer. Urban areas are distinguished from rural areas by developed infrastructure and transportation systems, and the availability of services and amenities.
<b>Use</b>	The term “use” of a health service refers to the action following the selection of a health service, to the actual engagement with the health service to meet a health need.

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## **Appendix B: Two-Eyed Seeing Integrative Review**

Two-Eyed Seeing is recommended by CIHR, NSERC and SSHRC as a guiding framework for research with Indigenous people in Canada (Bartlett, Marshall, & Marshall, 2012). To date, researchers have developed their own interpretations of the framework and what its application to research with Indigenous peoples entails. The original developers of Two-Eyed Seeing come from the field of education, and developed it to help with curriculum development. Although Two-Eyed Seeing has been described from a theoretical and philosophical standpoint in numerous papers, the literature remains vague in its practical application which has resulted in an inconsistent practice of Two-Eyed Seeing and confusion amongst researchers. To resolve the problem of confusion and clarify how Two-Eyed Seeing has been defined and used by researchers to date in any field of science, an integrative review guided by Whitemore and Knafl (2005) was completed. The Whitemore and Knafl (2005) approach involves five stages including (a) problem identification, (b) literature search, (c) data evaluation of quality, (d) data analysis and (e) data synthesis.

### **Methods**

#### **Literature Search**

Following the initial identification of the problem: the lack of a decisive definition and application of Two-Eyed Seeing to research, a systematic search of the literature was completed using OVID Healthstar, Embase, Medline, CINAHL and Pubmed databases and the search term: Two-Eyed Seeing. Additional search terms narrowed the results significantly and did not result in additional relevant articles. Articles were included if they were published in English and either defined and/or used Two-Eyed Seeing. Articles

were excluded from further review if they did not meet these criteria. (See Figure 1 below for a flow diagram of the search strategy and article selection.)

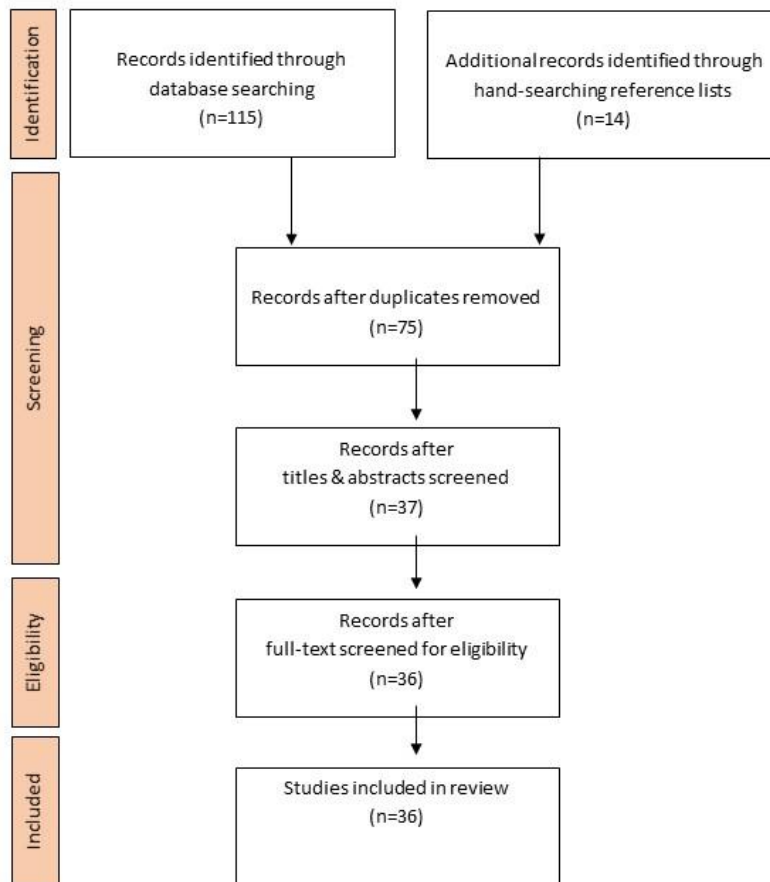


Figure 1. Flow diagram of search strategy and article selection

### Evaluation of Quality

Selected articles that were primary studies were then critically appraised for quality using an appropriate tool from the Critical Appraisals Skills Programme (CASP) library of appraisal tools (CASP, 2017a, 2017b) and the tool developed by Pluye, Gagnon, Griffiths, & Johnson-Lafleur (2009) for critiquing mixed methods research. The quality

appraisal was conducted to validate the quality of the extracted data included in the data analysis (see Table 1: Sample Critical Appraisal of Primary studies Resulting from Two-Eyed Seeing Literature Review), but this did not influence their inclusion in the analysis itself.

### **Data Extraction & Analysis**

Data relating to the definition and use of Two-Eyed Seeing were extracted separately from each article. Extracted data were placed into a table using Microsoft Word with one column for data related to definitions, and another column with data related to usage. Data in each column were further separated into educational and scientific research disciplines (See Table 2: Sample of Definitions and Applications of Two-Eyed Seeing in the Literature). During data analysis, data relating to the definition and utilization of Two-Eyed Seeing were analyzed separately and compared for similarities and differences. The constant comparison method as described by Miles and Huberman (1994) was utilized during this stage, comparing each piece of datum to another. Similarities in the groupings were initially sorted into codes and then further grouped to themes during the later stage of data analysis.

### **Results**

A total of 36 articles were included in the review, including 23 theoretical and review articles, 2 editorial papers, and 11 primary studies (9 qualitative studies; 1 quantitative study; 1 mixed methods study). A total of 9 articles were related to the field of education (curriculum development) and the majority (27) related to scientific research. Review articles (n=14) consisted of literature reviews of Two-Eyed Seeing (6)

and discussions on the real or theoretical application of Two-Eyed Seeing to primary research studies (8).

All but one of the qualitative studies (n=9) (Clark, 2014) demonstrated moderate to high methodological quality. Study limitations included inadequate descriptions of study methodology by four studies (Cabrera, Beattie, Dwosh, & Illes, 2015; Clark, 2014; Marsh, Cote-Meek, Young, Najavits, & Toulouse, 2016; Rand, 2016), inadequately addressing the potential influence of relationships between the researcher and participants by three studies (Cabrera et al., 2015; Clark, 2014; Whiting, Cavers, Bassendowski, & Petrucka, 2018) and insufficiently describing of how rigour was maintained during data analysis in five studies (Cabrera et al., 2015; Clark, 2014; Marsh et al., 2016; Martin, Thompson, Ballard, & Linton, 2017; Rand, 2016). The quantitative study although high quality, was not powered to show statistically significant results (Hunt et al., 2018). The mixed methods study (n=1) did not specify a mixed methods research design and did not adequately address rigour in the data analysis of qualitative data (Mantyka-Pringle et al., 2017).

### **Data Synthesis**

During the final stage of the review, data synthesis, three themes emerged including (a) defining characteristics of Two-Eyed Seeing, (b) required attributes of those engaging with Two-Eyed Seeing, and (c) Two-Eyed Seeing in research. These themes are presented in Table 3 and described below.

**Defining characteristics of Two-Eyed Seeing.** The original developers of Two-Eyed Seeing defined it as (a) an equitable approach to shared perspectives in which all



viewpoints are valued, an approach that, (b) extends the understanding of an integration of perspectives, using the best from each worldview, (c) is holistic and (d) requires a reflective approach. Those with differing worldviews must value working together with others to co-create knowledge and learn from and appreciate each other's differences. A holistic approach should be undertaken, considering the mind, body and spirit, and individuals must be reflective, examining their own perspectives, worldviews, beliefs and values. The analogy of trees holding hands beneath the ground (with their roots) is used to describe this joining together with one another despite our differences (Bartlett, Marshall, & Marshall, 2012).

Since its inception, new authors engaging with Two-Eyed Seeing have agreed with these defining features and expanded further on its concept. For example, several terms have since been used to describe the concept of integration including blending, weaving and merging. Yet Iwama et al. (2009), one of the original authors of Two-eyed Seeing, stresses this integration is not simply an amalgamation of perspectives in which pieces of Indigenous worldviews are merely pasted together with Western views, that it is a thoughtful integration of the best that each perspective has to offer to solve problems and leave the world a better place. Two-Eyed Seeing has more recently been defined as a conscious integration of Indigenous knowledge and worldviews, reflected by action-based approaches, requiring flexibility on the part of the researcher, and involving the Indigenous community in research including traditions and ceremonies (Hall, Dell, Fornssler, Hopkins, & Mushquash, 2015; Martin, 2012). Two-Eyed Seeing has more recently been considered a decolonizing approach, in that it stresses Indigenous

methodologies and worldviews and an equitable and collaborative approach to research with Indigenous people (Chambers et al., 2018; Hall et al., 2015; Iwama et al., 2009; Kapyrka & Dockstator, 2012; Martin, 2012). Other researchers have recently interpreted Two-Eyed Seeing as a strengths-based approach, as they perceive that the framework seeks to abolish negative stereotypes of Indigenous people being weak or vulnerable, and builds upon the strengths and resiliency of communities (Carter, Lapum, Lavallée, Schindel Martin, & Restoule, 2017; Chambers et al., 2018; Clark, 2014; Hatala et al., 2017; Hovey, Delormier, McComber, Lévesque, & Martin, 2017; Hunt et al., 2018; Latimer et al., 2014; Marsh et al., 2016; Rand, 2016). This more recent interpretation stresses the importance of recognizing the resiliency of Indigenous people. Finally, there is confusion in the literature as to whether Two-Eyed Seeing is a framework, a model, a theory, an ethical protocol or a guiding principle, often key terms are used interchangeably by the original and subsequent authors using Two-Eyed Seeing. Some suggest that Two-Eyed Seeing is much more than a set of prescriptive guidelines to ethical research with Indigenous people, in that it is a philosophy and a way of life that influences the entire research process from inception through to completion (Hall et al., 2015; Hovey et al., 2017). This perceived confusion likely stems from Two-Eyed Seeing being relatively new and it requiring further refinement in the literature.

**Required attributes of those engaging with Two-Eyed Seeing.** Since its development, authors have expanded on the required attributes of those engaging with Two-Eyed Seeing, adding ideas not previously emphasized by original developers. They recommend that researchers and educators using Two-Eyed Seeing should have effective

communication skills and be honest with those of differing worldviews and to build relationships (Kapyrka & Dockstator, 2012; Whiting et al., 2018). They should also be open to change, as embarking on initiatives using Two-Eyed Seeing is a largely new undertaking (Whiting et al., 2018). Individuals must engage in self-reflection, analyzing their own perspectives, beliefs and values and appreciate and value both commonalities and differences between the worldviews of all involved (Carter et al., 2017; Marsh, Coholic, Cote-Meek, & Najavits, 2015; Martin, 2012; Mckeon, 2012; Stephens, 2000). In doing so, individuals must also appreciate and understand spiritual wellness to truly engage with Indigenous perspectives (Rowan et al., 2015). All those involved must be patient, as the process of engaging with multiple viewpoints is time-consuming and often does not adhere to formal funding agency guidelines (Hall et al., 2015). Finally, those engaged in Two-Eyed Seeing should take a strengths-based perspective on research and education to build upon the strengths of Indigenous people, promote Indigenous self-determination and governance and not further perpetuate negative stereotypes (Carter et al., 2017; Marsh et al., 2015; Martin et al., 2017).

**Two-Eyed Seeing in research.** The use of Two-Eyed Seeing in research varies from author to author based on different interpretations of the framework and a lack of consistency in the literature concerning its use in research.<sup>8</sup> While some authors use Two-Eyed Seeing purely as a rationale to value different perspectives from those of mainstream or Western viewpoints (Cabrera et al., 2015; Clark, 2014; Latimer et al.,

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<sup>8</sup> The education literature (not including articles of foundational work), has been excluded here as these authors' application of Two-Eyed Seeing is related to curriculum development and not scientific research. These three articles include: Kapyrka & Dockstator, 2012; Mckeon, 2012; Stephens, 2000.

2014; Mantyka-Pringle et al., 2017; Paraschak & Forsyth, 2010), others incorporate its ideals throughout the research process in varying ways. Six components of the impact of Two-Eyed Seeing on the research process can be gleaned from the work of researchers who interpret the application of Two-Eyed Seeing as more than just appreciating a differing perspective from mainstream. These six components include (a) authentic relationships, (b) reciprocal research, (c) relational accountability, (d) Indigenous involvement, (e) Indigenous methodology and (f) Western researchers learning to follow. Not every component is enacted by all researchers, or carried out in the same way, but collectively these six components encompass how Two-Eyed Seeing has been applied in research to date.

First, authentic relationships between researchers and the Indigenous community with whom research is being conducted, including relationships with participants, is valued and regarded as important to ethical research with Indigenous people (Hatala et al., 2017; Marsh, Cote-Meek, Toulouse, Najavits, & Young, 2015; Martin et al., 2017; Rand, 2016; Whitty-Rogers, Caine, & Cameron, 2016). Research is reciprocal, meaning that not only do researchers benefit by gaining knowledge, answers to research questions or acknowledgement for their work, but participants also benefit as healing and wellness is promoted throughout the research process by building relationships and learning from one another (Fornssler et al., 2018; Hall et al., 2015; Whiting et al., 2018). Similarly, relational accountability is an expectation of researchers who by engaging with Two-Eyed Seeing assume responsibility for the health and well-being of the research team, community and participants throughout the research process (Chambers et al., 2018;

Hatala et al., 2017; Marsh, Cote-Meek, et al., 2015). This is accomplished by integrating traditional teaching, ceremonies and Elders into the research process. The involvement of the Indigenous community in research processes is common throughout this literature, though the extent varies. Indigenous Elders, knowledge holders and community members are involved in the research process, most commonly in the form of an Advisory council, which oversees and directs the study, and was initially advocated for by the original developers of Two-Eyed Seeing (Bartlett, Marshall, & Marshall, 2012; Carter et al., 2017; Hatala et al., 2017; Hovey et al., 2017; Marsh, Coholic, et al., 2015; Marsh, Cote-Meek, et al., 2015; Martin et al., 2017; Rand, 2016). In many cases, Elders or Indigenous researchers are actively involved in various aspects of the research, including recruitment, data collection, analysis, knowledge translation and may provide traditional teaching and ceremonies throughout (Chatwood et al., 2015; Fornssler et al., 2018; Hall et al., 2015; Hatala et al., 2017; Hunt et al., 2018; Marsh, Cote-Meek, et al., 2015; Martin et al., 2017; Rand, 2016; Rowan et al., 2015; Whiting et al., 2018; Whitty-Rogers et al., 2016). In this review, most researchers recognized and valued local Indigenous customs and traditions and sought guidance prior to initiating research with the Indigenous community. Research designs were commonly influenced by Indigenous ways of knowing through the selection of methods that respected oral tradition (such as storytelling) (Fornssler et al., 2018; Hall et al., 2015; Rand, 2016), adapting Western methodologies for Indigenous ways of knowing (such as grounded theory) (Hatala et al., 2017), engaging in member checking with participants to validate findings (Carter et al., 2017; Whitty-Rogers et al., 2016), integrating land-based activities (Chatwood et al., 2015) and incorporating traditional

teaching and ceremonies throughout the research process (Fornssler et al., 2018; Hall et al., 2015; Hatala et al., 2017; Marsh et al., 2015; Rowan et al., 2015; Whiting et al., 2018). Finally, some researchers, described the role of Western researchers in Two-Eyed Seeing to be that of follower, listener and learner as the original developers also described. To complete research using Indigenous ways of knowing and methodologies, Western researchers must be willing to take a back seat and allow others with Indigenous knowledge and lived experience to lead the research process (Fornssler et al., 2018; Hall et al., 2015; Iwama et al., 2009; Rowan et al., 2015).

From the review of this literature, it is clear that Two-Eyed Seeing is continually developing based on interpretations of those who apply it. More recent applications of Two-Eyed Seeing have resulted in its conceptualization as a decolonizing methodology and a strengths-based approach. Many researchers have integrated Two-Eyed Seeing ideals throughout the research process, involving Indigenous communities in the development of research questions and protocols, and forming authentic and lasting relationships. As the application and development of Two-Eyed Seeing continues to mature, its identification as a model, framework or theory may begin to emerge, as researchers bring clarity and add to concepts, relationships and assumptions.

A limitation of this review is that themes have been developed from published literature, and publishing restrictions may have resulted in authors not adequately describing their application of Two-Eyed Seeing in research. To mitigate this limitation in future, researchers should consider writing an additional publication to thoroughly describe their interpretation and application of Two-Eyed Seeing.

**Towards a comprehensive understanding of Two-Eyed Seeing.** There are commonalities and differences in how researchers have interpreted and applied Two-eyed seeing. This likely results from its origins in education and the subsequent applications to health research. The developers of Two-Eyed Seeing used a philosophical approach to describe it in their early work and suggested applications to curriculum development rather than to research. The adoption of Two-Eyed Seeing by funding bodies has resulted in a number of researchers attempting to apply it without clear examples of how to do so. This has resulted in confusion in the literature regarding definitions and application of Two-Eyed Seeing. Certainly, applying all the elements of Table 3 to research, will ensure that research is likely to be congruent with other decolonizing approaches and founded in Indigenous methodologies and ways of knowing. Application of Two-Eyed Seeing to research needs to be used authentically and not in simplistic terms. In fact, this misuse risks undermining the entire premise of Two-Eyed Seeing as an egalitarian approach to collaborative research. Instead, researchers should engage in a thoughtful period of self-reflection to first determine if they can embrace the attributes necessary to undertake research using Two-Eyed Seeing, and, if so, take care to adopt and apply a set of factors (Table 3) to their research approach. Researchers should take care to thoroughly describe their approach to Two-Eyed Seeing to enable other researchers and Indigenous communities struggling to understand its practical application. Going forward, a comprehensive definition and appropriate application of Two-Eyed Seeing are called for so that researchers can ensure its authentic use in future research.

**Use of Two-Eyed Seeing in this study.** In this study Two-Eyed Seeing was used as a conceptual lens, prompting collaboration, consultation and the opportunity to learn from Indigenous knowledge holders early in study development and through each stage of the research. Initially, Elders and members of the Indigenous community in Hamilton were approached for their involvement in development of the proposal, as the study design unfolded they agreed that the research questions were in alignment with the priorities of their communities.

Numerous attempts were made to engage Elders throughout the research process but were unsuccessful, as they did not have time to be involved. At present Elders are committed in activities related to the TRC recommendations. To ensure Indigenous perspectives and ways of knowing were adequately integrated into the research, a Métis scholar joined the researcher's Supervisory committee and a First Nations Nurse from Six Nations on the Grand River joined the study as a research assistant and cultural advisor. Both individuals contributed to the study design and guided the entire research process to help ensure decisions were aligned with local customs and traditions and Indigenous ways of knowing. From the start, the research assistant was engaged in opportunities for training, knowledge and skill acquisition as a priority to help build research capacity in the local First Nations community.

Building relationships with the Indigenous community was essential and valued as an important initial step in the research process. The researcher also began to establish relationships with individuals from Indigenous organizations in Hamilton two years prior to embarking on the research. The researcher and research assistant attended community



events and mother/baby classes at the Indigenous Friendship centre to build relationships, foster understanding and trust with staff and potential participants prior to initiating recruitment.

While a Western methodology, ID, guided this study, the principles of Two-Eyed Seeing influenced the selection of methods, data analysis and knowledge translation activities. First, the use interviews and the discussion group were selected as modes of data collection to honour the value of oral tradition to Indigenous people (CIHR, NSERC, SSHRC, 2014). Second, the presence of the research assistant during interviews was offered to participants on the recommendation of Indigenous community members who felt mothers might be more comfortable if an Indigenous individual were present. Third, the offering of tobacco was initially considered for use as a sign of respect prior to data collection, but was decided against as Indigenous advisors felt not all urban-dwelling Indigenous mothers have strong ties to Indigenous traditions and therefore may not understand or appreciate its symbolic meaning. In addition, the participants included both First Nations and Métis individuals who do not all partake in the sharing of tobacco as a traditional custom. Fourth, participant mothers were offered refreshments of their choice and a cash honorarium during data collection, as a sign of respect and appreciation of their time. The honorarium consisted of a fair hourly wage as required by employers in Ontario, so as to adequately and respectfully compensate the mothers. Finally, a discussion group brought all the participants together to discuss the initial data analysis, confirm the presence of emerging themes, and to clarify questions arising from the data. The researcher and research assistant provided a meal and a communal craft prior to

discussing the research findings. This helped to further strengthen the relationships and trust within the group and allowed for other group members to meet new friends, share stories and caring for one another, potentially resulting in healing and wellness, an important feature of decolonizing research methodology (Marsh et al., 2016). The remaining craft supplies were left for use by the Indigenous Friendship centre as a donation and contribution to their important programming.

Two-Eyed Seeing greatly influenced data analysis, and highlighted that analysis required a collaborative effort between researcher and research assistant to use both Western and Indigenous perspectives. Both the researcher and research assistant completed data analysis separately and then came together over several months to compare and contrast results. The research assistant was instrumental in illuminating cultural nuances in the data relating to the impact of residential schools on family dynamics, as well as local traditions, slang and politics that arose from the data.

Finally, Two-Eyed Seeing has influenced knowledge translation efforts, as these are community-led and consist of more than typical presentations of the findings to the academic community through publications and presentations at conferences. First, it was important to acknowledge the research assistant throughout dissemination activities, as it is not only the researcher who should gain recognition for this work. Second, upon completion of this doctoral program, the researcher intends to work with the Indigenous community in Hamilton to further disseminate the findings in ways identified as effective and necessary by the community itself. The researcher remains in ongoing conversations with the Indigenous community in Hamilton related to these ventures, and in particular,

with the Indigenous Friendship centre that assisted greatly with participant recruitment. The researcher remains committed to fostering research knowledge and skills in the Indigenous community to promote Indigenous researchers and self-governance.

### **Strengths and Limitations**

The literature compiled in this review represents what is currently available within mainstream databases where some Indigenous journals may not be indexed. The review also did not include unpublished PhD dissertations. As such, some literature using Two-Eyed Seeing may not have been captured in this review. Secondly, all but one of the primary studies included in this review utilized qualitative methodology, and adequate reporting of details pertaining to methodology is often difficult due to publication word restrictions. Thus, descriptions of the application of Two-Eyed Seeing in the research process may be further impeded as most included papers were from qualitative studies and may have caused this author to misinterpret an absence of details as a gap in the application of Two-Eyed Seeing.

### **Conclusions**

A thorough review of the literature was undertaken to better understand how Two-Eyed Seeing is defined and used in research. This review is in response to inconsistencies noted in the literature, however findings suggest both commonalities and differences in the interpretation and application of Two-Eyed Seeing. This review has synthesized the literature to reflect comprehensive definitions of Two-Eyed Seeing, identified the required attributes of researchers engaging in Two-Eyed Seeing and applications of Two-Eyed Seeing to research. The results of this review are useful to researchers wishing to

engage with Two-Eyed Seeing and to better understand its characteristics and application to research. Researchers engaging with Two-Eyed Seeing should thoughtfully consider how best to apply Two-Eyed Seeing to their research and clearly reflect and describe these decisions in their manuscripts. A more consistent interpretation and application is required if Two-Eyed Seeing is to grow into a well-defined model to guide future research.

Table 1

*Sample Critical Appraisal of Primary Studies Resulting from Two-Eyed Seeing Literature Review*

Study	CASP Qualitative Checklist									
	Clear purpose	Appropriate for qualitative research	Appropriate design for research question	Recruitment method fitting	Data collection fitting question	Relationship between researcher & participants considered	Ethics considered	Rigor in data analysis	Clear results	Valuable results
Cabrera et al. (2015)	Yes	Yes	Yes, though methodology is not described  Community-based research  n=48	No, secondary data analysis	Yes  Semi-structured focus groups	No	Yes  Complied with Nation’s ethics protocol & University ethics board	Not described.  Content analysis	Yes  Understanding of disease is medicalized/Western, but approach is both Western & Indigenous	Yes  Validates presence of both views for those who require this proof in order to value different perspectives of health & wellness
	Impact of medicalization on FN group’s knowledge and approaches to wellness in relation to early onset familial Alzheimer disease									
	British Columbia FN community									

*Note.* Checklist includes: CASP Qualitative Study (CASP, 2017a)

Table 2

*Sample of Definitions and Applications of Two-Eyed Seeing in the Literature*

		<b>Manuscript</b>	<b>Methodology/ Study Design</b>	<b>Definitions of Two- Eyed Seeing</b>	<b>Applications of Two-Eyed Seeing</b>
<b>Education</b>	<b>Foundational Work</b>	Bartlett, Marshall & Marshall (2007)	Report of Integrative science program at Cape Breton University, Nova Scotia	Commonalities exist between Indigenous and Western perspectives and deserve respect Journey together Co-learning Weaving back and forth between the best of both world views	We all need each other in this journey Learning must be by <i>doing</i> Knowledge gardening—sharing and growing knowledge with others Visuals assist in understanding Institutions of higher learning must integrate Indigenous knowledge into curriculums
	<b>Curriculum Development</b>	Mckeon (2012)	Applying Two-Eyed Seeing in elementary education	Co-learning journey Requires self-location (examining one’s own beliefs and values and how these differ from others)	Integrating storytelling Holistic approach Providing land-based education Working in collaboration with an Indigenous Elder
<b>Scientific Research Studies</b>	<b>Qualitative</b>	Cabrera, Beattie, Dwosh, & Illes (2015)	How FN group affected by early onset familial Alzheimer disease understands the condition and related health behaviours	Theoretical framework Appreciation of both Indigenous and Western ways of knowing Used to understand differences between health approaches, environmental planning, education and policy.	Provides rationale for appreciating and valuing both Indigenous and Western perspectives
	<b>Quantitative</b>	Hunt, Michalak, Lefkimmatis, Johnston, Macumber, Jocko & Ouchterlony (2018)	Quasi-experiment time series study to determine effectiveness of intervention on knowledge retention pertaining to concussion head injury	A principle Bringing together the strengths of both Indigenous and Western ways of knowing	Partnership with FN community Collaborative intervention with FN nurse and nurse from local hospital University and community ethics approval
	<b>Review</b>	Hovey, Delormier, McComber, Lévesque & Martin (2017)	Review of application of Two-Eyed Seeing in a community-based research project on diabetes prevention	Creates ethical space for health promotion Find common ground between different perspectives Weave perspectives into new understanding Differing perspectives are a strength Not merely a method or a prescriptive list Requires relational approach, sharing of ideas	University & community ethics board approvals Community advisory group Use of traditional Haudenosaunee decision making process Humility and belief in equality Commitment to project

*Note.* Shortforms: FN First Nation

Table 3

*Summary of Results*

<p><b><u>Defining Characteristics of Two-Eyed Seeing</u></b></p> <ol style="list-style-type: none"> <li>1. Equitable, all perspectives valued</li> <li>2. Some amount of blending, merging, integrating; using both perspectives together</li> <li>3. Decolonizing approach</li> <li>4. Strengths-based approach</li> <li>5. Researcher must be reflective of their own perspectives/beliefs/values</li> <li>6. Co-learning with each other; togetherness, working together; commonalities &amp; appreciating differences</li> <li>7. To the betterment of all, leave the world a better place</li> <li>8. Some amount of impact on research design: action based, flexible, holistic approach, Indigenous involvement, involvement of Indigenous traditions/ceremony in research</li> <li>9. Confusion as to framework vs. theory vs. ethical protocol vs. guiding principle</li> <li>10. Uses: Understanding differences in health approaches, environmental planning, education, health policy, problem solving, applicable to other cultures, mixed methods, respond to and resolve conflicts, linguistic components of health, incorporating minority cultures into education, treatments for substance use, meet challenges</li> </ol>
<p><b><u>Required Attributes of those Engaging with Two-Eyed Seeing:</u></b></p> <ol style="list-style-type: none"> <li>1. Good communication skills</li> <li>2. Honest with one another</li> <li>3. Open to change</li> <li>4. Appreciate and understand spiritual wellness</li> <li>5. Patience in the process</li> <li>6. Take a strengths-based perspective</li> <li>7. Engage in self-reflection on own perspectives, beliefs and values</li> <li>8. Acknowledge and value commonalities and differences in perspectives</li> </ol>
<p><b><u>Two-Eyed Seeing in Research:</u></b></p> <ol style="list-style-type: none"> <li>1. Authentic relationships between researchers, community and participants</li> <li>2. Reciprocal—both researchers and participants benefit through research (promotion of healing and wellness, building relationships, learning from one another)</li> <li>3. Relational accountability—researchers are responsible for the well-being of the research team, participants and community, by promoting healing and wellness (often through traditional teaching and ceremony)</li> <li>4. Indigenous involvement—Elders, knowledge holders and community members involved throughout research process (commonly in form of Advisory council), actively involved in methods, local customs are respected and incorporated</li> <li>5. Indigenous ways of knowing form foundation of research design (respect oral tradition, methods/methodologies in line with Indigenous ways of knowing, land-based, active and based on <i>doing</i>, member-checking for rigor, incorporation of traditional teaching and ceremonies, promote healing and well-being)</li> <li>6. Western researchers must be willing to take a back seat, be followers, listeners and learners in the process</li> </ol>

## Appendix C: Sample Interview Guide

### Indigenous Mothers Interview Guide

Version 5: December 12, 2016

Thank you for agreeing to meet with me to discuss how you use health services to meet your baby's health needs.

#### Introductory Questions

- Can you tell me a bit about you and your baby?
- Can you tell me what has been one of your most surprising things about being a mom?
- We're going to draw a circle to represent you in the middle of this page, and another circle (female) or square (male) below you to represent your baby.
- Who are you living with?
- Do you care for other children?
- Are these daughters or sons, or both? I'll draw circles or squares to represent them as well.
- Can we write your age and the age of your children as of today, in these circles and squares?
- What has your baby's health been like since she/he's been born?

OK you've told me a lot about how your baby's health has been since being born. I'm really interested in understanding more about how we can create better health care services to support moms like you. I'd like to begin to talk about all the different people and services that you have connected with to care for your baby's health. While we do this, I'm going to draw a map of the services we talk about.

#### Section 1: Prevention/health promotion

1. What are the things you've done to keep \_\_\_\_ healthy? To make sure she doesn't get sick?

Prompts:

- a) do you ask questions of Mom/Grandmother/friends?
- b) family doctor for immunizations?
- c) public health nurse?
- d) electronic resources?
- e) ceremonies when baby is born to keep baby healthy?
- f) traditional medicine to keep baby healthy?
- g) Elders or community members help to keep baby healthy?

For each listed:

- a) What was the health service or person?
- b) Why did you go to that service/person?
- c) When you worked with this service/person, what was that experience like for you?
- d) Did you find the service/person met your baby's needs?
- e) What did you like most about that service/person? Why?
- f) What would you change? Why?



- g) Was there something you didn't like?
- 2. Let's look at the services you've said you use to keep your baby healthy. One at a time, I want you to think about which of your baby's health needs they meet. Do they meet your baby's physical, mental, emotional or spiritual needs, some, or all of these? I'll make note of these by the service name.
- 3. Again, let's look at the services you've said you use to keep your baby healthy. This time, let's draw a really thick line if this service is really important to meeting your baby's health needs, thin if it isn't as important, and a line with strikes through it if you find it stressful to use this service to care for your baby.

### **Section 2: Treatment**

1. How do you know when your infant is healthy/sick?
2. Have there been times when your baby has been sick?
3. Let's do the same thing as before, and make a list of which health services or people you have connected with when your baby has been sick.

Prompts:

- a) do you ask questions of Mom/Grandmother/friends?
- b) family doctor?
- c) public health nurse?
- d) electronic resources?
- e) ceremonies?
- f) traditional medicine?
- g) Elders or community members?

For each listed:

- a) What was the health service or person?
  - b) Why did you go to that service/person?
  - c) When you worked with this service/person, what was that experience like for you?
  - d) Did you find the service/person met your baby's needs?
  - e) What did you like most about that service/person? Why?
  - f) What would you change? Why?
  - g) Was there something you didn't like?
4. Let's look at the services you've said you use to keep your baby healthy. One at a time, I want you to think about which of your baby's health needs they meet. Do they meet your baby's physical, mental, emotional or spiritual needs, some, or all of these? I'll make note of these by the service name.
  5. Again, let's look at the services you've said you use to keep your baby healthy. This time, let's draw a really thick line if this service is really important to meeting your baby's health needs, thin if it isn't as important, and a line with strikes through it if you find it stressful to use this service to care for your baby.

### **Section 3: Long-term/Follow up services**

1. Are there any health conditions that your baby has that require your baby to continue to

be followed by a health service or person? (ie. Growth issues, breathing issues like asthma, developmental delay).

2. Which health services or people do you use to deal with this health condition?

Prompts:

- a) do you ask questions of partner/Mom/Grandmother/friends?
- b) family doctor?
- c) public health nurse?
- d) electronic resources?
- e) ceremonies?
- f) traditional medicine?
- g) Elders or community members?

For each listed:

- a) What was the health service or person?
- b) Why did you go to that service/person?
- c) When you worked with this service/person, what was that experience like for you?
- d) Did you find the service/person met your baby's needs?
- e) What did you like most about that service/person? Why?
- f) What would you change? Why?
- g) Was there something you didn't like?

3. Let's look at the services you've said you use to keep your baby healthy. One at a time, I want you to think about which of your baby's health needs they meet. Do they meet your baby's physical, mental, emotional or spiritual needs, some, or all of these? I'll make note of these by the service name.

4. Again, let's look at the services you've said you use to keep your baby healthy. This time, let's draw a really thick line if this service is really important to meeting your baby's health needs, thin if it isn't as important, and a line with strikes through it if you find it stressful to use this service to care for your baby.

### **Concluding Questions**

- Of all the services we've talked about today, which were the most positive and why?
- Which were the most negative and why?
- What would the most ideal health service look like? Why?
- Have you ever not been able to find the help you needed for your baby's health?
- Has there ever been a time when your baby had some health concerns for which there was a service you would have like to have accessed but couldn't?
  - Which services/people?
  - What were the reasons why you couldn't access that service?
- Is there anything else about your baby's health that you would like to share with me?

### **Appendix D: Consulted Community Organizations**

The following organizations were approached prior to initiation of the research proposal and approved of the research question, initially proposed study design, and/or that they would assist with participant recruitment.

Hamilton Regional Indian Centre:

Family Support Coordinator

Director of Aboriginal Healthy Babies, Healthy Children

De dwa da dehs nye>s Aboriginal Health Centre:

Executive Director

Manager of Clinical Services

Dr. Janet Smylie, Associate Professor, Dalla Lana School of Public Health, University of Toronto, CIHR Applied Public Health Chair

Ontario Native Women's Association, Hamilton

Aboriginal Healthy Babies, Healthy Children home visitor Program Coordinator

Dr. Dawn Martin-Hill, McMaster University, Associate Professor, Department of Anthropology and Indigenous Studies Program; Paul R. MacPherson Chair in Indigenous Studies

Dr. Bernice Downey, McMaster University, Assistant Professor, Indigenous Health Initiative Lead, School of Nursing/Department of Psychiatry & Behavioural Neuroscience, Faculty of Health Science; Regional Aboriginal Cancer Lead, Toronto Central Region, Cancer Care Ontario

Elder in Residence Program, ASHS, McMaster University  
Myeengun Henry, Elder, Chippewas of the Thames

Niwasa Preschool

Early Words Program Manager, Ketmanee Prabadsri

Dr. Peter Fitzgerald, President, McMaster Children's Hospital

Dr. Stacey Marjerrison, Assistant Clinical Professor, Department of Pediatrics, McMaster University

Hamilton Coalition for Healthy Birth Weights, Public Health, Hamilton  
Health Strategy Specialist, Health Promotion Specialist



## Appendix E: Consent Form (Mothers)

### An invitation to take part in research



**Study Title: The experiences of urban-dwelling Indigenous mothers in Ontario in selecting and using services for the health of their infants: An interpretive description.**

**Name of Principal Investigator: Dr. Olive Wahoush**

**Name of Local Principal Investigator: Amy Wright**

**Funding Source: CIHR Fellowship—Priority Announcement: Research in First Nations, Métis and/or Inuit Health, Funding Reference Number 146613**

Thank you for taking the time to read information about this study. Your participation is voluntary and if you agree to take part and change your mind, you can withdraw at any time. These decisions will not affect any of the health care you receive in Hamilton, in any way.

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#### **What is this study about?**

Canadian Indigenous infants experience higher rates of birth complications and death rates than do non-Indigenous infants. Living in urban areas in Canada where there are more health services does not seem to improve health outcomes. Mothers tend to make sure their babies stay healthy, by bringing them to see nurses, doctors and healers, but some studies say that Indigenous mothers may delay, or not seek medical care for lots of reasons such as past experiences with racism and a lack of support for traditional medicine. We do not fully understand how Indigenous mothers living in urban areas in Canada select and use health services to care for the health of their infants, and how access to health services might be improved to promote their infant's health.

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

The purpose of this study is to learn about how Indigenous mothers select and use health care services in Hamilton to meet the health needs of their infants. The results will help shape how health care services are delivered to Indigenous mothers, infants and their families in Hamilton.

#### **What will happen to the participants in this study?**

If you agree to participate, the researcher will book a time to meet with you wherever you feel most comfortable, to discuss your experiences in an interview. During the interview, the researcher will make notes about the location and information about emotions or body language. This information will help the researcher understand your feelings about the

topic. The interview will be audio recorded so that the data can be transcribed and analyzed.

When the interviews have been completed with all the mothers in the study, you will be asked to

join in a discussion group, where mothers who participated in the study will meet to discuss the findings together. You will have the chance to confirm that the results of the study reflect your experience, and to make sure that there is no incorrect or missing information. During the discussion group, the researcher will make notes about the location, how many people were there, and information about emotions or body language. This information will help the researcher understand how people feel about the topic. The discussion group will be audio recorded so that the data can be transcribed and analyzed.

**What are the risks of this study?**

There are no known risks of participating in this study. You will have the chance to ask the researcher to remove any of the information you shared during the interview or discussion group that you are uncomfortable having included in the study results. If any of the information that you share makes you feel upset, you will be offered information on available counseling services in Hamilton with whom you can discuss your feelings.

**What are the benefits of this study?**

Through participating in this study, you will have the opportunity to share your experiences and have your voice heard. The information you share will be used to help other Indigenous mothers care for the health of their infants. You will be helping to improve how health care services are delivered in Hamilton.

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

You will be given an honorarium of 20 dollars to participate in the interview. You will also be given refreshments prior to the interview and discussion group. Any bus fare or parking costs to attend the interview or discussion group will be covered.

**Will there be any costs to me to participate in this study?**

No.

**How will the privacy of your personal information be protected?**

During the study, you will be asked for your personal information such as your name, your gender, your phone number and your email address so we can contact you to inform you of the discussion group event. Your personal information will be kept completely confidential (except as required by law).

For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the Hamilton Integrated Research Ethics Board may consult your

research data. However, no records which identify you by name will be shared. By signing this consent form, you authorize such access.

We will protect your personal information by:

- Storing the information in locked cabinets in a locked office.
- Assigning you a number that will be used to identify you during the study. Only the research team will know this number.
- Any results that are published or shared with others will not have any information that would identify you.

**Who should I contact if I have questions?**

If you have questions or need more information, please contact

Amy Wright, Local Principal Investigator, of the study.

McMaster University, School of Nursing

905 929 2048

wrighal@mcmaster.ca

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). If you have questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board, at 905.521.2100 x 42013.

### Research study consent form

**Study Title: The experience of urban-dwelling Indigenous mothers in Ontario in selecting and using services for the health of their infants: An interpretive description.**

Please check each statement to indicate your consent:

- I have read the information about this study being conducted by Amy Wright of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to take part in this study, I may withdraw from the study at any time, without penalty to me.
- I understand that no information that would identify myself will be released or printed without my permission
- I understand that I may be contacted to clarify and confirm study findings, and to join in a sharing circle.
- I understand the interview and sharing circle will be audio-recorded
- I agree to take part in the study.
- I have received a signed copy of this form

My name: \_\_\_\_\_ (please print)

Signature: \_\_\_\_\_

Date: \_\_\_\_\_ (yyyy/mm/dd)

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Name of person  
obtaining consent: \_\_\_\_\_ (please print)

Signature: \_\_\_\_\_

Date: \_\_\_\_\_ (yyyy/mm/dd)

**Appendix F: Application of the Tri Council Policy Statement 2, Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada**

Article #	Title	Implications	Application in this study
9.1	Requirement of community engagement in Aboriginal research	Engage community in research	<ul style="list-style-type: none"> <li>•Consulted with Indigenous community members &amp; organizations in Hamilton</li> <li>•All approve of research question and study design</li> <li>•Collaboration with Indigenous community member as research assistant throughout research project</li> </ul>
9.2	Nature and extent of community engagement	Determine jointly by researcher & community, appropriate to community characteristics and nature of the research	<ul style="list-style-type: none"> <li>•Community members and organizations have been offered engagement and collaboration with the project.</li> <li>•Organizations generally willing to participate with participant recruitment</li> <li>•Indigenous community member as Research assistant</li> </ul>
9.3	Respect for First Nations, Inuit and Métis Governing Authorities	Where proposed research is to be conducted on Indigenous lands, researcher must seek engagement of formal leaders of community	<ul style="list-style-type: none"> <li>•N/A</li> <li>Research to be conducted in Hamilton, off-reserve.</li> <li>•Approval has been sought from numerous Indigenous community members and organizations in Hamilton.</li> </ul>
9.4	Engagement with Organizations and communities of interest	Recognize Aboriginal organizations, through representation of their members on the project where appropriate	<ul style="list-style-type: none"> <li>•Numerous Indigenous community members and organizations have been consulted with and offered collaboration on the project.</li> </ul>
9.5	Complex authority structures	Engage community and document measures taken to report to REB and demonstrate consideration of complex community authority structures	<ul style="list-style-type: none"> <li>•Numerous Indigenous community members and organizations have been consulted with and offered collaboration on the project.</li> <li>•Approval of research by ethics boards</li> </ul>
9.6	Recognizing diverse interests within communities	Ensure safety of vulnerable individuals, ensure special measures to reach those most vulnerable to ensure they are included in the study	<ul style="list-style-type: none"> <li>•Mothers met at a place convenient to them to conduct interviews.</li> <li>•All mothers interested in participating who fit the inclusion criteria participated in an interview.</li> <li>•Multiple sites of recruitment via posters &amp; participation in community events</li> </ul>



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9.7	Critical inquiry	Research that critically examines the conduct of public institutions or organizations exercising authority over Indigenous individuals should be conducted ethically	<ul style="list-style-type: none"> <li>•N/A</li> <li>•All efforts made to ensure study is conducted ethically and in a culturally appropriate manner through submission to REB, and review by Indigenous community members</li> </ul>
9.8	Respect for community customs and codes of practice		<ul style="list-style-type: none"> <li>•Involving Indigenous community member as research assistant to ensure protocol and procedures are culturally appropriate</li> <li>•Using culturally appropriate data collection methods (interviews &amp; discussion group)</li> </ul>
9.9	Institutional Research Ethics Review Required		<ul style="list-style-type: none"> <li>•HiREB, Mohawk REB &amp; McMaster University Family Medicine Research board approvals</li> </ul>
9.10	Requirement to advise the REB on a plan for community engagement		<ul style="list-style-type: none"> <li>•See above</li> </ul>
9.11	Research agreements	Terms and undertakings of both researcher and community should be communicated through a research agreement prior to participant recruitment	<ul style="list-style-type: none"> <li>•Written agreements between researcher and community organizations in regards to placement of recruitment posters &amp; attendance at community events for the purpose of recruitment</li> </ul>
9.12	Collaborative research	Apply a collaborative approach appropriate to nature of research and level of ongoing engagement desired by community	<ul style="list-style-type: none"> <li>•Numerous Indigenous community members and organizations offered collaboration with project and to approve on research question and research design.</li> </ul>
9.13	Mutual benefits in research	relevant to community needs and priorities, benefit participating community	<ul style="list-style-type: none"> <li>•Study results to benefit Indigenous population in Hamilton by providing essential information needed to improve access to health services.</li> </ul>
9.14	Strengthening research capacity	Support capacity building through enhancement of skills in research methods, project management, ethical review and oversight	<ul style="list-style-type: none"> <li>•Indigenous community member as research assistant will learn research methods, assist in data collection and analysis and dissemination activities.</li> <li>•Participants will be offered to participate in study via data analysis. No participants were interested in participating this way.</li> </ul>
9.15	Recognition of the Role of Elders and other	Engage Elders to participate	<ul style="list-style-type: none"> <li>•Elder has been approached through McMaster ASHs program, but unable to participate due to time constraints.</li> </ul>

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	knowledge holders		<ul style="list-style-type: none"> <li>•Indigenous community member involved as research assistant, also had understanding of Indigenous culture, tradition and ceremonies.</li> </ul>
9.16	Privacy and Confidentiality	Address these early in the community engagement process. Determine level of disclosure of personal information that will be disclosed to community partners. Researchers will not disclose without participant's consent.	<ul style="list-style-type: none"> <li>•Consent obtained prior to any data collection or participation in the research study</li> <li>•Participants had opportunity to confirm which data will be included in the study and which they would like removed from the transcripts</li> <li>•All data de-identified (ie: specific place of residence, occupations, any names, etc)</li> <li>•Results confirmed via member checking prior to sharing findings</li> </ul>
9.17	Interpretation and dissemination of research results	Afford community representatives engaged in the collaborative research an opportunity to participate in interpretation of data and the review of research findings before completion of final report and publications.	<ul style="list-style-type: none"> <li>•Participants offered opportunity to participate in the research Advisory Group, but all declined</li> <li>•Organizations approached have denied the opportunity to participate in data analysis due to lack of resources and time.</li> </ul>
9.18	Intellectual Property Related to Research	Intellectual property rights should be discussed and agreed upon before research is conducted.	<ul style="list-style-type: none"> <li>•Community organizations who participate in the study will be acknowledged in any reports or dissemination activities (Hamilton Regional Indian Board)</li> <li>•Findings and data will be available to any community members.</li> <li>•Dissemination activities will involve community organizations (Hamilton Regional Indian Centre) and community members</li> </ul>
9.19	Collection of human biological materials involving Aboriginal peoples		<ul style="list-style-type: none"> <li>•N/A</li> </ul>
9.20,	Secondary use of	Where research relies only	•N/A
9.21,	data and human	on publicly available	
9.22	biological material identifiable as originating from an Aboriginal community or peoples	information or on legally accessible information, community engagement is not required REB review is required where the researcher seeks data linkage of two or more anonymous datasets	

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