PRETERM BIRTH: PERSPECTIVES ON RESOURCE ACCESS AND PREGNANCY
EXPERIENCE

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ABSTRACT

Pregnancy is affected by multiple factors both within and outside of a woman's control. For those who experience a preterm pregnancy, considerations about their experiences can be revelatory and meaningful in understanding concepts such as information sharing, support systems, and care models. This research uses qualitative description to further enhance our knowledge about women's preterm birth experiences within the Hamilton Niagara Haldimand Brant (HNHB) Local Health Integration Network (LHIN). Participant interviews (n=13), key informant interviews (n=2), and participant observations were conducted. Findings exposed 6 themes: 1) prenatal preparedness; 2) working while pregnant; 3) delivery expectations; 4) place and space; 5) supports and resource attainment; and 6) attitudes and knowledge. Collectively, the themes point to the need for improvements in service delivery and knowledge acquisition, and also suggest a new paradigm of employment involvement in pregnancy as well as reaffirmed or rebranded client-provider expectations during pregnancy.

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1. Introduction

Preterm birth is not something that health care providers can easily predict (Lockwood, 2002). As a maternal and infant birth outcome, it is becoming more widely understood. Maternal and infant birth outcomes are affected by women's access to resources and services, in conjunction with many other psychosocial, socioeconomic, behavioural, and biological influences (Behrman & Butler, 2007). Preterm birth outcomes are steadily being explained by neighbourhood and national level data, but less so at small community or individual levels. This is problematic because there are documented disparities in health - both across and between regions/communities (Behrman & Butler, 2007). Also, policy and practice interventions in health care are primarily dealt with at the regional/local level in Ontario, Canada, where community input is essential (Barker, 2014).

The relationship between system characteristics and individuals in accessing primary health care services highlights the need for a greater focus on local-level health care access issues (Wellstood et al., 2006). Further, there is need for better linkages between place and utilization/access to health care (Law et al., 2005). With regard to preterm birth experiences in particular, Phillippi & Roman (2013) have developed a model to understand what motivates and what facilitates women's access to prenatal care. For example, accommodating women's life scheduling for after-hours prenatal appointments is a facilitator, whereas the maternal variable of now being able to and wanting to attend the appointment is a motivator (Phillippi & Roman, 2013). Last, observing the impacts of

neighbourhood-level environmental contexts on birth outcome inequalities demonstrates how space and place interplay to support adverse birth outcome inequalities (Meng et al., 2013). Community-level interventions with more contextual considerations in adverse birth outcome research is a starting point, but the involvedness of social and individual considerations will be instrumental in following up on community strategies and policy implementations in the future (Meng et al., 2013).

Question & Objectives

For the purposes of this thesis, the scope of prenatal health care access and utilization has been explicitly broadened to include the non traditional aspects of prenatal health care that include the benefits of having a support system, participating in prenatal classes, and generally having sufficient knowledge to care for oneself and one's unborn child. It will later be made clear that these extra considerations positively improve and complement the standard, traditional definition of prenatal care.

In an effort to inform practical community-level interventions, the objectives of this study are i) to learn more about women's pregnancy perceptions and experiences, and further, ii) to specifically capture the ways in which preterm birth mothers within the Hamilton Niagara Haldimand Brant (HNHB) Local Health Integration Network (LHIN) accessed prenatal health care and resources during their pregnancies.

The research question asks: *How are women's pregnancy experiences influenced by perceptions of access?*

The following chapter will review pertinent literature concerning preterm births, access and utilization characteristics, maternal perceptions and experiences, situate research context within health geography, and describe applicable conceptual frameworks. This will provide a solid foundation to understand the descriptions and exploration of themes and concepts presented in the following chapters.

2. Literature Review

The literature review will cover the topics of preterm birth and relevant indicators, health care access and utilization, health and medical geography, and maternal perceptions of pregnancy and birth characteristics. Reviewing these topics will promote an understanding of the gaps in the literature, the research rationale, and the conceptual frameworks used to conduct the research presented.

2.1 What is Preterm Birth?

Preterm birth is defined as birth before the expected delivery date of 40-42 weeks gestation. Typically, a birth is considered preterm if it occurs at less than 37 weeks gestation (Simmons et al., 2010; CIHI, 2009). The prevalence of preterm birth can be used as an indicator of maternal health, and infant mortality and morbidity (Beck et al., 2010; Wen et al., 2004). Premature labour impacts both the mother and baby's emotional

and physical well-being (Beck et al., 2010). Some health complications of the child that are linked to their preterm birth include, but are not limited to, developing respiratory distress, hearing and vision problems (Ward & Beachy, 2003), temperature instability, seizures, and apnoea (Saigal & Doyle, 2008).

The short- and long-term health complications of preterm births are a costly burden on the health care system, especially considering that preterm birth is the leading cause of neonatal death globally, accounting for 27% of all neonatal mortalities (Liu et al., 2012; Simmons et al., 2010). Given the possible lasting effects of prematurity, such as a significantly higher risk of developing cerebral palsy (Saigal & Doyle, 2008), it is difficult to identify the actualized total cost of preterm birth on the health care system. Direct and indirect costs can include hospital night stays in the neonatal intensive care unit (NICU), work-labour costs of extreme care for preterm infants, and lost hours of productive work for the parents and later, the child. In 2005, the Committee on Understanding Premature Birth and Assuring Healthy Outcomes in the United States estimated that the typical lifetime cost of one preterm birth was approximately $51,600 USD, including several direct and indirect costs such as medical and educational intervention costs, and lost labour market productivity (Behrman & Butler, 2007). The Canadian Institute for Health Information (CIHI) estimated in 2006 that a typical preterm admission to hospital accounted for approximately $4,600 CAD based on the immediate medical resources used during the stay (salaries, drugs, equipment, etc.). Considering that approximately 7-9% of all births in Canada are premature, amounting to approximately

19,000 premature births a year (CIHI, 2012; BORN, 2012), the simple hospital admission of mothers giving a preterm birth accounts for over $87 million per year. The cost needs to be addressed, especially as the Canadian cost estimate does not consider any of the long term and affiliated effects of premature births.

In 2005, there were approximately 11-12.9 million preterm births worldwide; by 2010, that number rose to approximately 15 million (Beck et al., 2010; Chang et al., 2013). The 2005 estimate of the preterm birth rate of North America (10.6%) and Africa (11.9%) were both very similar and the highest in the world (Beck et al., 2010), which may be surprising given one contains primarily developed countries and the other developing countries. However, there may be notably different factors contributing to such high preterm birth rates across these locations: in North America, age at the time of pregnancy may be a contributing factor, whereas in Africa, intrauterine infection, or limited access to prenatal care may be a more prominent contributor (Chang et al., 2013), although the causality of these associations is yet to be determined.

2.1.1 Preterm Birth Risk Factors

It is important to first acknowledge that there is no direct, all encompassing cause for preterm birth. There are many factors that increase a woman's risk for having a poor birth outcome, and in this case, a preterm birth outcome. According to the Canadian Premature Babies Foundation (2016), some of the causes of preterm birth are: irregular prenatal care, high blood pressure, stress, multiples in pregnancy, a previous premature birth, low

body mass, chronic illness, smoking, and overworking. Behrman & Butler (2007) distinguish the factors associated with preterm birth as upstream initiators or downstream effectors: upstream initiators are plentiful and include factors that may eventually contribute to the likelihood of a preterm birth (e.g., maternal stress and exercise), whereas downstream effectors are few and include the specific processes that necessarily occur during a preterm birth (e.g., uterine contractions and membrane rupture). Factors that can ultimately lead to a premature birth are also considered part of the causal pathways and mechanisms that can mediate various contributors of preterm birth (i.e. socioeconomic status) (Kramer et al., 2001). These are not to be confused with clinical predictors of preterm birth, which are somewhat better understood, such as the monitoring of biomarkers, monitoring of uterine activity, using vaginal sonography, or using some other measure related to labour to predict the time of birth (Lockwood, 2002; Krupa et al., 2006). However, even predicting preterm labour is still not fully understood, and is part of the multidimensional nature of preterm birth. Any plausible contributing factors to preterm birth occurrences will from this point be referred to as risk factors.

Commonly documented risk factors can be categorized into behavioural, psychosocial, socioeconomic, and biological factors. Individual level behavioural risk factors for preterm birth refer to behaviours that could affect birth outcome. Among others, diet, exercise, and smoking are considered to be behavioural risk factors for preterm birth (Behrman & Butler, 2007). For instance, pregnant women who exercise approximately 30 minutes a day are significantly less likely to have a preterm birth (Juhl et al., 2008;

Schonberg & Williams, 2014). Additionally, behavioural factors are very easily confounded with a number of other lifestyle or biological factors. This could be because of participant recall bias, the stigmas associated with certain behaviours while pregnant, and because they are so related to upstream factors such as socioeconomic status that casual relationships are generally difficult to make (Behrman & Butler, 2007).

Psychosocial factors that influence birth outcome include, but are not limited to, maternal anxiety, stress, and support. These factors are difficult to understand well because of the issues previously discussed in identifying causal relationships among multiple factors (Green et al., 2005; Behrman & Butler, 2007). Support and stress are known to be independent risk factors for poor birth outcome (Kramer et al., 2000), and particularly of preterm birth outcome (Nkansah-Amankra et al., 2010). For instance, a lack of social support during pregnancy may be a barrier to accessing prenatal care (Heaman et al., 2014), while increased information acquisition-style social support may improve birth outcomes from premature populations (Shapiro et al., 2013).

The relation of the socioeconomic status of mothers to poor birth outcomes has been studied by looking at low birth weight and intrauterine growth, and more recently preterm birth (Kramer et al., 2000). For the most part, socioeconomic factors consider categorizations of income, education, and marital status. For example, work is an indicator of socioeconomic status, and is related to better health outcomes through improved quality of life – satisfaction, health benefits, and more discretionary income

(Behrman & Butler, 2007; Saurel-Cubizolles et al., 2004). However, work alone is not a *measure* of socioeconomic status, and should not automatically be considered beneficial because long demanding work hours and affiliated stress affects risk for preterm birth (Saurel-Cubizolles et al., 2004).

Biological risk factors often concern the downstream effectors of preterm birth, and are clear markers or predictors of preterm birth. Examples of biological risk factors include recurrent premature labours and uterine infections (Lockwood, 2002). Biological risk factors are often very distinct and not easily confounded with one another, making them significantly different than the previously identified behavioural, psychosocial, and socioeconomic factors. However, biological risk factors are better understood retroactively, as there are still vast barriers in predicting preterm births (Behrman & Butler, 2007; Lockwood, 2002).

2.2 Health Care Access & Utilization

Behavioural, psychosocial, socioeconomic, and biological risk factors are all affected by the affected party's access to relevant resources. This study will focus largely on the issue of access within the overall pregnancy experience as per the psychosocial and behaviour factors involved in poor birth outcomes, namely preterm births.

For now, let us define access as the ability to obtain health care given structural and social constructs, and given one's motivations; and let us refer to utilization as the actual uptake

of care. The social determinants of health (e.g., education, employment, income) contribute significantly to the access and utilization pathways for health care and health resources. The social determinants of health have been studied for decades and results overwhelmingly suggest that social and economic disadvantage are linked to health (Braveman et al., 2011). Additionally, health and health care access are affected by many other factors, such as scale, location, and diversity (Galea et al., 2005).

The literature reflects a broad array of health care utilization and access research, but is primarily related to access to specialized services, such as mental health care or cancer care (Eisenberg et al., 2007; Onega et al., 2008), access differentials across large-scale spaces (i.e., provinces, rural vs. urban, countries) (Schuurman et al., 2010; Sibley & Weiner, 2011; Lasser et al., 2006), and across vulnerable populations or those with disadvantages, such as immigrants (Dixon-Woods et al., 2006; Lasser et al., 2006; Zuvekas & Taliaferro, 2003; Fiscella et al., 2002). Additionally, most of the research in health care access maintains a focus on generalizable neighbourhood variables, rather than taking advantage of unique community differences.

The issues of health care access and utilization have been studied in various contexts. There are variations in care access across large-scale regions such as between the US and Canada (Lasser et al., 2006), and between urban and rural regions (Sibley & Weiner, 2011). Although health care coverage is a major determinant in accessibility to care seen across nations, it does not downplay other factors such as marital status, which is also

quite telling of access (Lasser et al., 2006; Zuvekas & Taliaferro, 2003). Rural habitants tend to use services less, such as fewer visits to health care practitioners, and are especially less likely to see specialists (Allan & Cloutier-Fisher, 2010). In addition, living further away from a city or urban centre is associated with less access and utilization of resources such as flu vaccinations (Sibley & Weiner, 2011). Moreover, vulnerable populations are unlikely to obtain the same amount of resources or access to health care as those less vulnerable populations, as measured by race, education, and job status, amongst others (Dixon-Woods et al., 2006). Disadvantaged and poorer populations also have less access to health care, often caused by a lack of information and financial means, as well as varying geographic and social constraints (Peters et al., 2008). Those with more educational and financial advantage have more access, but the barriers to health care seem to also be concerned with psychosocial and behavioural factors (Joseph et al., 2007).

2.2.1 Maternal Access to Health Care and Health Resources

Pregnant women face many of the same social, economic, and spatial determinants or associations to poor health as any other population. However, pregnant women have the unique characteristic of having short- and long-term health outcomes for themselves, in addition to impacting the short- and long-term health outcomes of another human being. After 9 months gestation, a newborn's health has been predetermined by the constraints under which the mother lived by. When studying access considerations in antenatal health, we can ask questions such as: Did the mother have barriers to attending doctor's visits? Did she live in an area where emergency care was of poorer quality or quantity?

Did she have access to healthy food options? Critically, we should be asking why she felt or did not feel that she needed to get care or seek out resources in the first place and explore their over all pregnancy experiences.

Access to health care services, and specifically access to prenatal and obstetric care, is known to be associated with poorer birth outcomes (The Chief Public Health Officer of Canada, 2009; Nesbitt et al., 1990). Access in this sense can refer to geometric access to services or socio-economic access barriers and facilitators. To elaborate, those in rural areas are less able to obtain care for reasons of doctor availability (Nesbitt et al., 1990), and those of lower socioeconomic status are more likely to have poor birth outcomes such as gestational diabetes or small-for-gestational age births (Joseph et al., 2007). Additionally, access to prenatal care can be affected by, but likely not limited to, late recognition of pregnancy, perceptions on the type and quality of care, trustworthiness of the health care providers, and the availability of personal resources such as time and money (Downe et al., 2009).

Limited access to prenatal care may be also a result of upstream variables such as less social support (Buka et al., 2003). In fact, Hendryx et al. (2002) conclude that access to social capital in a community increases access to health care uptake. Social capital, specifically social supports that improve health, include participating in civic activities, having friends and trust in the community and services, having access to information, and having feelings of mutual obligation or of feeling cared for (Hendryx et al., 2002; Crnic et

al., 1983). Due to relationships like this, it is important to consider more upstream variables in antenatal access, such as information/knowledge gain, and trust in health care/doctors, because they impact the decisions of mothers to access health care services in the first place, and contribute to making healthy decisions.

Trust in doctors is a factor known to have implications for continued use, and agreeability on medical recommendations, and can have an impact on communication between doctors and patients (Mainous et al., 2001). Harrison et al. (2003) concluded that women who have higher risk pregnancies (e.g., those with gestational diabetes) often trusted their physician to make active health care decisions for and with them. However, the same pregnant women also wanted to make their own health decisions, given they had access to information that would help in making those healthy choices (Harrison et al., 2003). Women in this study reported getting their information from the prenatal care team in the hospital and from within the community. Health information, though, is increasingly being found online. In a study on internet usage and health care information, it was found that about two thirds of the participants (n=6369) accessed the internet for health related queries (Hesse, 2005). Of the participants who sought health-related information online, they were mostly women and were of higher socioeconomic status; additionally, trust in that information was inversely related to age (Hesse, 2005). Trust, social capital, and availability of information seem to be motivators in accessing health resources and in making health care decisions.

2.3 Medical and Health Geography

Medical geography has historically focused on geographical contributions to disease and health care (Kearns & Joseph, 1993). However, this definition of medical geography has shifted out of focus for human geographers. Human geographers today focus on the 'geography of health' or 'health geography', which extends beyond looking at disease and medicine through a geographic lens. Specifically, health geography is focused on promoting a broad social understanding of human well-being, with a large focus on the individual (Kearns & Moon, 2002). The transition from medical to health geography came from defining the differences and reconciling the cohesion between space and place in medical health research (Kearns & Joseph, 1993). Additionally, situating health care issues relationally allows health geographers to be contextually aware and more focused on place (Cummins et al., 2007). Particularly, including the context of place and space in health research leads to a greater understanding of health inequalities, which is a large focus of health geography research (Curtis & Rees Jones, 1998). Understandably then, disciplines both within *and* outside of geography can be understood by situating research with the overall theme of place, which can lead to theory generation (Kearns & Moon, 2002). For example, Andrews (2002) identifies the theoretical links between nursing and medical/health geography as a consistently changing health care setting, while considering the role of people, culture, and place. Health geography studies that investigate health across place and space, as well as the individual characteristics, all assist in identifying differences in health (Curtis & Ress Jones, 1998). Consequently, as health geography is a critical study, it tends to be more theory building, Also, it often uses

more qualitative methods (Kearns & Moon, 2002). For example, Burke et al. (2006)

studied the factors that facilitated intimate partner violence in various neighbourhoods.

Using mixed-methods, the accounts from participants and concept maps helped to

increase understanding of the neighbourhood contexts and relate it to health outcomes

(Burke et al., 2006). In creating studies in this more social and qualitative vain,

researchers can practice critical social theory, a pillar of the study of health geography

(Kearns & Moon, 2002).

The study of maternal well-being and preterm birth, or even more broadly, the study of

adverse birth outcomes within the frame of medical geography and/or health geography

has not been practiced overtly for very long. One of the earlier examples of health

geography within the maternal and newborn field of study is that of Gober (1997) who

investigated women's abortion rates across areas in the US. Though, specifically to

preterm birth, the majority of the literature in this area is represented by medically

focused analyses on neighbourhood-level variables and the connection to various adverse

birth outcomes (e.g. Pickett et al., 2002; O'Campo et al., 2008). Additionally, compared

to preterm births, more frequently studied adverse birth outcomes are small for

gestational age and low birth weight births (e.g. Farley et al., 2006). A baby born small

for their gestational age, often lighter in weight, is considered closely tethered to preterm

birth, but is not the same thing and should not be used as a proxy for similar outcomes,

i.e. low birth weight (Goldenberg et al., 2008; Behrman & Butler, 2007). The frequent but

inaccurate practice of not distinguishing small for gestational age and preterm birth

children demonstrates the need for thorough and explicit research of preterm births.

2.3.1 Level of Analysis in Maternal Health Research

Maternal and infant health care research has studied both quantitative and various

individual level associations of preterm birth or other adverse birth outcomes. Take Wen

et al. (2004), who found that smoking, among other factors (low or high maternal weight,

race, etc.) are in fact associated with a higher risk for prematurity. Similarly, many other

factors such as exercise (Juhl et al., 2008) or having low body mass (Goldenberg et al.,

2008) have been studied to find some effect on prematurity, but context and locality is

often left out of the picture. However, in looking at individual level factors like smoking

during pregnancy, the possibility for confounded variables, like socioeconomic status, is

quite likely (Behrman & Butler, 2007). This type of limitation is a motivating factor in

conducting more multi-level studies that help to broaden our scope of understanding

premature birth outcomes.

A growing number of studies are seeking more than just individual level associations, and

are then making broader conclusions about demographic and contextual relationships to

preterm birth and neighbourhood. For instance, Farley et al. (2006) studied the

relationship between neighbourhood and adverse newborn outcomes (small for

gestational age and prematurity) using a multi-level analysis and census tract data, where

they found associations of neighbourhood income characteristics to birth outcome

independent of individual factors. However, it was still noted that more multi-level and theoretical study is needed to fully understand the interactions between environment/neighbourhood and birth outcomes (Farley et al., 2006). Also, consider Nkansah-Amankra et al. (2010), who were among the first to analyze neighbourhood deprivations of income inequality and social support with respect to birth outcomes. This study found that social support had an independent relationship to birth outcomes of low birth weight and prematurity, where medium-level income inequality was only associated with low birth weight. Diez Roux & Mair (2010) implore that more studies in general be done linking daily activities and psychosocial processes (e.g., social support) with spatial context. A promising avenue to explore some of these types of psychosocial processes is by qualitative analysis, which is much more recently becoming recognized in the maternal and infant health literature.

2.4 Maternal Perceptions of Pregnancy and Childbirth Experiences

Some of the benefits of using qualitative analyses to study birth experiences are outlined here. Particular attention will be given to the perceived experiences of care and access barriers. Although some qualitative analyses may limit the generalizability of the research compared to the examples we have seen above, they do provide a thoroughly in depth understanding of issues that come straight from the participant's perspectives.

In asking women about their experiences of childbirth, women identify that the close people in their lives (loved ones, spouse, parent) provide them with emotional support

and contribute to a positive birth experience (Tarkka & Paunonen, 1995). The largest

perceived role in their positive birth experience comes from the aid of their primary care

provider (PCP) and their own immediate family members (Tarkka & Paunonen, 1995;

Gibbins & Thomson, 2001). On the other hand, women with less perceived social support

show more signs of stress, depression, and anxiety (Glazier et al., 2004). Those who have

more social support typically show less signs of stress, as the support is seen as a

mediating factor to more positive birth outcomes (Glazier et al., 2004; Shapiro et al.,

2013).

Reading books and attending prenatal classes helps women to prepare for pregnancy and

birth, and ultimately aids in their confidence (Declercq et al., 2007; Gibbins & Thomson,

2001). Feeling confident is beneficial for a number of reasons, including maintaining a

positive outlook on the overall experience (Declercq et al., 2007). Negative experiences

due to hearing unsettling information or not feeling prepared for giving birth can facilitate

higher anxiety in subsequent pregnancies for that mother (Melender, 2002), which can

have implications for their current and next birth outcome. Fear plays into confidence and

preparedness as well, and is a dominant feeling among pregnant women (Declercq et al.,

2007). Women's fears throughout pregnancy are from a broad range of issues, such as

fears for childbirth, well-being for self and baby, family issues, and also fears concerning

health care providers (Melender, 2002).

Furthermore, women report feeling uncomfortable with making various decisions related to their pregnancy. For example, women report their discomfort with the responsibility of deciding the mode of delivery, and would prefer that their PCP provide curated information for them that suggests the best route for their pregnancy (Moffat et al., 2007). It is important to note that despite being uncomfortable with certain decisions, women still want to be included in decision-making throughout the labour process (Gibbins & Thomson, 2001). In fact, women are always resorting to the Internet to find supplementary information, to network for support, and to ultimately increase their confidence in pregnancy decision-making (Lagan et al., 2010). This is increasingly becoming more apparent as women are requiring more tailored information, and the Internet is the leading way to address those needs and to help women feel less isolated (Lowe et al., 2009).

Prenatal care has an influence on birth outcome and maternal feelings as well. Women who access their full prenatal care recommendation show better birth weight outcomes than those who do not (Kogan et al., 1994). Not only are women influenced by prenatal care in terms of advice and procedural attributes, but they are also influenced by their expectations and perceptions of the prenatal care they receive (Sword, 2003). When it comes to accessing prenatal care, women report having many barriers such as, but not limited to: motivation to begin care (Phillippi, 2009), time, location, cost (Ickovicks et al., 2007), and attitudes of care staff (Melender, 2002).

2.5 Conceptual Frameworks

In understanding health care access and utilization by populations and individuals, a review on accessibility to care frameworks along with the health belief model will be addressed. A short focus on their applications in the literature will be mentioned. These conceptualizations of access and health belief will help tailor this research and position it contextually. These frameworks have informed the research study and function as point of reference and reliability.

2.5.1 Access

Access to care has been considered a conceptual framework for over 50 years. Aday & Anderson (1975) grew this framework's popularity in the literature by outlining the terms and conditions under which populations gain entry to care systems and to what extent these same systems are usable based on actual utilization and satisfaction.

To begin, Aday & Anderson's (1975) framework focuses on 'populations at risk' – the organization and resources of health care services (treatment, travel time, etc.) and a person's willingness to receive care. Willingness is characterized by the three overarching factors that make a person decide whether or not they are going to use a service. The first of the group is the *predisposing* component, which considers the more pre-existing properties of a person such as age, sex, and values. The second is the *enabling* component, which considers the resources of that person and the attributes available to them in the community that gives them the wherewithal to use a service (e.g., what is the

region like spatially and financially?). Third is the *need* component, which serves as either a perceived need to use a service or a need bestowed upon one by the care system. Additionally, both the utilization of health services and the satisfaction of services are considered in this model.

Table 1 - Concept of access definitions. Modified from Penchansky & Thomas (1981)

Availability	The relationship of the volume and type of existing services (and resources) to the clients' volume and types of needs. It refers to the adequacy of the supply of physicians, dentists, and other providers; of facilities such as clinics and hospitals; and of specialized programs and services such as mental health and emergency care.
Accessibility	The relationship between the location of supply and of clients, taking account of client transportation resources and travel time, distance, and cost.
Accommodation	The relationship with how the supply resources are organized to accept clients (including appointment systems, hours of operation, walk-in facilities, telephone services) and the clients' ability to accommodate to these factors and the clients' perception of their appropriateness
Affordability	The relationship of prices of services and providers' insurance or deposit requirements to the clients' income, ability to pay and existing health insurance. Client perception of worth relative to total cost is a concern here, as is clients' knowledge of prices, total cost, and possible credit arrangements.
Acceptability	The relationship of client's attitudes about personal and practice characteristics of providers to the actual characteristics of existing providers, as well as to provider attitudes about acceptable personal characteristics of clients. Refers mostly to specific consumer reaction to such provider attributes as age, sex, ethnicity, type of facility, neighbourhood of facility, or religious affiliation of facility of provider. In turn providers have attitudes about the preferred attributes of clients of their financing mechanisms. Providers either may be unwilling to serve certain types of clients (e.g., welfare patients) or, through accommodation, make themselves more or less available.

Among adjunct or similar access model derivatives (See: Khan & Bhardwaj 1994; Powell, 1995), Penchansky & Thomas (1981) later refined the concept of access into a simple framework of definitions that are more broadly applicable to researchers due to the decreased ambiguity of terms and more operational definition.

Penchansky & Thomas' (1981) definition of access (Table 1) illustrates the five access to care dimensions of availability, accessibility, accommodation, affordability, and acceptability. Additionally, this concept of access includes service utilization and satisfaction of clients while addressing the variable interactions between and among all factors. For instance, a service being too expensive may impact a client's utilization, which may lead to lower satisfaction – and inversely, if a client is unsatisfied, they may be less likely to use a service (Penchansky & Thomas, 1981). The definitions of terms are noticeably similar to the enabling considerations in Aday & Anderson's (1995) framework; as well the inclusion of utilization and satisfaction concerns are included in both frameworks. However, the streamlined and broad scope of Penchansky & Thomas' (1981) framework is more readily usable because it is less restrictive in defining connections among and between variables such as contextual, political, and structural variables.

Access Frameworks in Research

In practice, variations on these frameworks for usability and access are employed extensively. Take for example a conceptual framework merged from the merits of Aday & Anderson (1975) and Penchansky & Thomas (1981) where an assessment of a vulnerable population's health care access was studied. Peters et al. (2008) wanted to focus on care quality using concepts of supply and demand in health care service use. Using the overarching concepts of quality, accessibility, availability, affordability, and acceptability, Peters et al. (2008) concluded that local policies focused on better

financing, regulations, and delivery of services are most constructive in tackling access to health care. Further, Penchansky & Thomas' (1981) definition(s) of access have been referenced to better conceptualise accessibility in terms of distance (Pilkington et al., 2010), and to illustrate interactions among given dimensions of access (Fried et al., 2013).

2.5.2 Health Belief Model

The health belief model has been growing into what it is today since the 1950s and is borne out of the works of social psychologists trying to make sense of public health concerns surrounding failures in disease prevention (Rosenstock, 1974). Of course the model can be tailored to other health concerns aside from disease. The model as is concerns the individual cognitive push-and-pull factors of health behaviour decision-making (Rosenstock, 1974). Refer to Figure 1; notice that there are a number of factors that lead to the likelihood of taking action on a health preventive measure. The model puts emphasis on individual perceptions of disease attributes, while recognizing that there are many possible influences on behaviours – or rather on perceived benefits and barriers. Some of those influences – or rather modifying factors – are demographics, social class, external prompts like advice from others, and media campaigns.
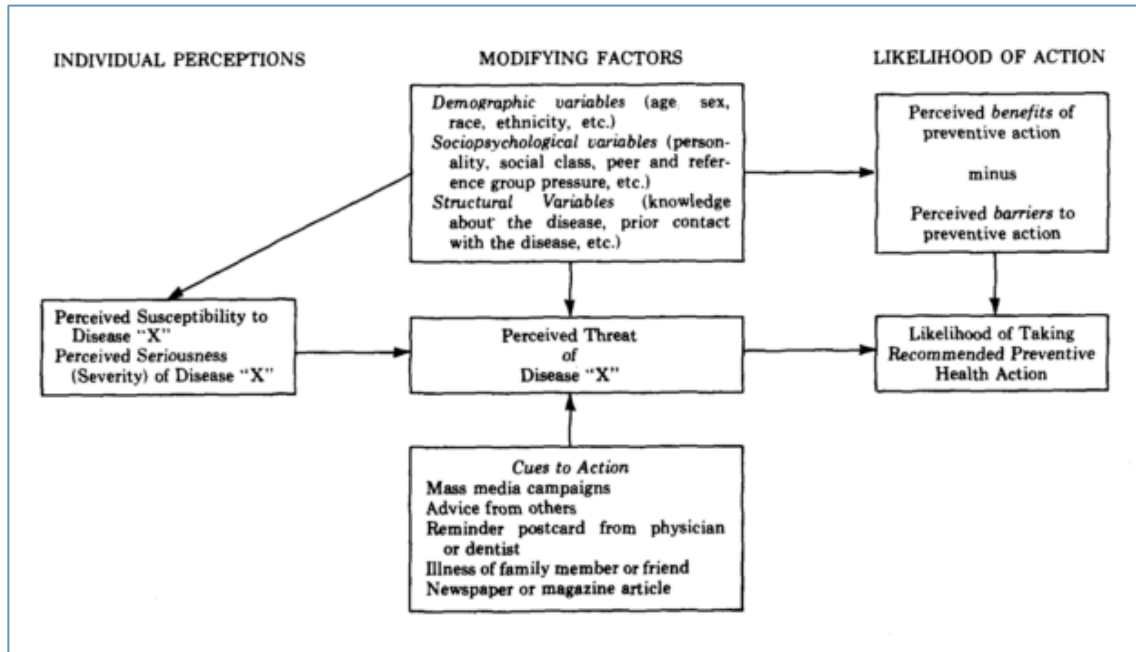
Health Belief Model in Research

The model was originally used for investigating the psychosocial process involved in

screening rates/tests for diseases such as TB, polio, and cervical cancer, but is now more

widely used across many health care domains (Rosenstock, 1974). The health belief

model has been used to identify what predicts health decisive action in individuals. Much

like the access framework above, most of the research that employs a health belief model

focuses on one or few aspects of the model. Consider Hounton et al.'s (2005) study on

barriers to condom usage, where perceived susceptibility (of transmitting Human

Immunodeficiency Virus, HIV) was the main focus of the model addressed.

The health belief model has been applied to areas such as women's uptake of breast

cancer screening, AIDS protective behaviour, and uptake of prenatal care. Yarbrough &

Braden (2000) used the model to identify some of the beliefs and values of women

considering breast cancer screening. Moreover, the health belief model is very fitting for

studies concerning prenatal care or pregnancy related health concerns, decisions, and

behaviours due to the compatibility of the proposed process and the nature of prenatal

care programming (Stout, 1997; Phillippi & Roman, 2013). Stout (1997) used the model

to explain the need for comprehensive prenatal care, considering all aspects that factor

into aligning mothers' perceptions of care and barriers with the reality of and benefit of

attending prenatal care. Stout (1997) even conceptualized the health belief model in

relation to prenatal care and illustrated that application – see Figure 2.

CUES TO ACTION

* Trigger to seek prenatal care: reminder cards, mass media, advice from others, etc.

THREAT EXPECTATIONS

* Perceived Susceptibility to delivering a low birth weight baby

* Perceived Severity of the consequences of delivering a low birth weight baby

MODIFYING FACTORS

* Demographic Variables influencing the decision to seek prenatal care: education, marital status, income, age

* Sociopsychological Variables: culture

* Structural Variables: accessibility to health care

OUTCOME EXPECTATIONS

* Perceived Benefits of prenatal care

* Perceived Barriers to prenatal care

EFFICACY EXPECTATIONS

* Perceived confidence in personal ability to achieve adequate prenatal care

LIKELIHOOD OF

TAKING ACTION

FIGURE 1 Application of the health belief model to prenatal care programming. *Note.* From "The Health Belief Model: Explaining Health Behaviors Through Expectancies," by I. Rosenstock. In K. Glanz, F. M. Lewis, and B. K. Rimer (Eds.), *Health Behavior and Health Education: Theory, Research, and Practice* (pp. 39–62). San Francisco: Jossey–Bass. Copyright 1990 by Irwin M. Rosenstock. Adapted with permission.

Figure 2 - Health Belief Model applied to prenatal health uptake (Stout, 1997)

Also, the model has been conceptualized more loosely, but still effectively; consider

Willett et al. (2010), who investigated the perceived career threats (see 'Threat

Expectations' in Figure 2) when considering having a child (see 'Likelihood of Taking

Action' in Figure 2). The health belief model is a function of psychosocial variables, and

can therefore be applied to many health-social focuses, as illustrated above.

3. Methodology

3.1 Research Setting

3.1.1 Local Health Integration Networks – HNHB

The region of focus for this study is the Hamilton Niagara Haldimand Brant (HNHB)

Local Health Integration Network (LHIN). The Ontario government sectioned the

province into distinct LHINs (depicted in Figure 3), characterized by regional geographic

boundaries, in an effort to promote local health care management (HNHB LHIN, 2014).
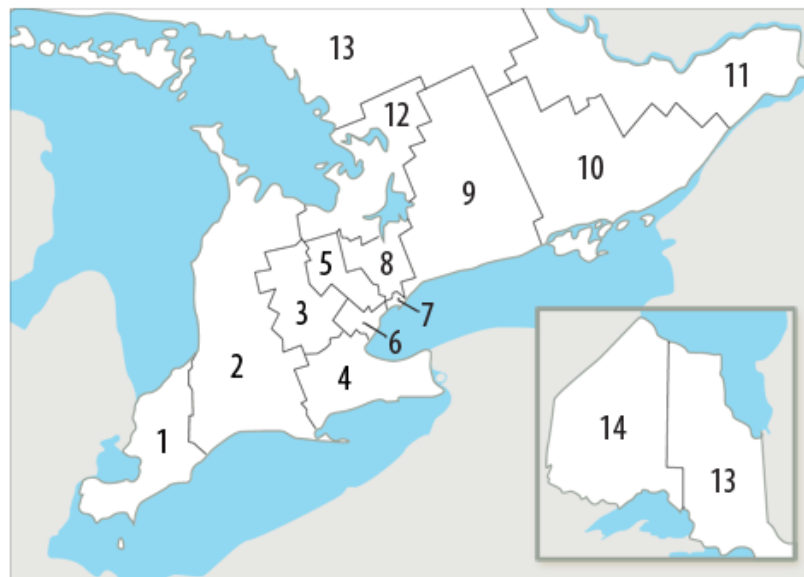
Figure 3 - Local Health Integration Network boundary map (Government of Ontario, 2014)

Ontario LHINs function in tandem with the Ministry of Health and Long Term Care

(MOHLTC) as community-level decision-makers for regional health care planning,

funding, and integration (Elson, 2009; HNHB LHIN, 2014). LHINs are a large part of the

more decentralized health care era that Canada has transitioned into over approximately the last 15 years (Elson, 2009; MNSC, 2007). LHINs are beneficial not only for policy makers and planners, but especially for the recipients of the health care system, because solutions are tailored to best suit individual community needs.

The study area of Hamilton Niagara Haldimand Brant (HNHB) LHIN (area 4 in Figure 3) is also inclusive of Burlington and Norfolk. The region includes a population of over 1.4 million, and is projected to increase 3.5% by 2020 (Ontario's LHINs, 2015). The area has variable socioeconomic characteristics, but in comparison to the rest of Ontario, HNHB has higher percentages of: smoking, heavy drinking, obesity, urban center population, and medical specialists (HNHB LHIN, 2014; Ontario's LHINs 2009). HNHB is below the Ontario average in the percentage of post-secondary graduates and family doctors. The region is on par with Ontario averages in low income, perceived health, and life expectancy (Ontario's LHINs 2009).

Given that LHINs cover a broad geographic range, it cannot be assumed that an entire region's characteristics are homogenous. For instance, in Hamilton, part of the HNHB LHIN, there is a longstanding 21-year gap in life expectancy across North Hamilton and the Southwest Mountain (DeLuca et al., 2012), yet Hamilton has, compared to the rest of Ontario, a similar average age of life expectancy (Ontario's LHINs, 2009).

Hamilton has a comparative average (61.7%) of perceived good/excellent health to the rest of the HNHB LHIN (61.5%), while Burlington has the highest perceived good/excellent health (66.5%) in the region (Ontario's LHINs, 2009). Hamilton has the most obese/overweight population (60.3%), whereas Burlington has the least obese/overweight population (49.4%) compared to the rest of HNHB. Similarly, the percentage of low-income households within HNHB is highest in Hamilton (18.1%), and lowest in Burlington (8.5%).

3.1.2 Maternal and Infant Health in HNHB Region

The Canadian average age at first birth has risen considerably in recent decades to 28.5 years, and the fertility rate in Canada is continually dropping in tandem with an aging population (Statistics Canada, 2013). In the HNHB region, there were close to 13,000 births in the 2009-2010 fiscal year, where 62% of those births were from women aged 25-34; also 45.6% of which were from nulliparous women (first time mothers) (BORN, 2011).

The leading diagnoses responsible for acute care hospitalization for all residents in the HNHB region are related to pregnancy and birth – live born infants and complications during pregnancy, labour, and delivery (Ontario's LHINs, 2009). Compared to the rest of Ontario, HNHB's hospitalization rates are significantly higher (Ontario's LHINs, 2009). The 2007 rate of preterm birth (10.2%) in HNHB was much higher than the Ontario average (7.9%) (MNSC, 2007). However, given more recent statistics from 2010 (BORN,

2011), HNHB's preterm birth rate (8.5%) seems to be converging with the provincial average (8.2%).

Within each LHIN, there are associations contributing to LHINs better serving their communities. For example, the Provincial Council for Maternal and Child Health works with a team of health and social service experts from across the LHIN regions (PCMCH, 2016), and functions to increase knowledge on the needs of maternal-child health care, as well as acts as a resource for support improvement and delivery of services across Ontario.

3.2 Research Design

3.2.1 Qualitative Methods

Qualitative methods are employed in social and health research, where there is typically a focus on social and cultural context on some given phenomenon (Neergaard et al., 2009; Ratner, 2002). This style of research uses detailed descriptions from documents or personal perspectives to paint a detailed picture of a situation or problem (Marshall & Rossman, 1999; Bryman & Teevan, 2005). Qualitative methods can thus be used to gain a deeper understanding of human experiences and social circumstances (Marshall & Rossman, 1999). Qualitative methods are considered subjective to some extent because of the researcher's job to interpret participant experiences, and decide its contribution to the culture of a given phenomenon (Ratner, 2002). A large part of qualitative research is

defining assumptions and expectations before data collection or analysis in order to avoid misleading avenues (Maxwell, 2011), which is the purpose of this section.

3.2.2 Qualitative Description

Initially, a case study design was thought to be the best approach to this research. At the time, the study was going to focus on two regions that showed high preterm birth rates, but had very opposing socio-cultural contexts. It would have been quite interesting to use two cases in a comparative fashion, but as research is iterative, and the sampling posed great challenges, the focus, questions, and constraints of the study changed. However, qualitative description was found to be a fitting method to guide this study.

Purposeful sampling and open-ended, semi-structured interview style is the preferred design approach used in qualitative description (Neergaard et al., 2009; Sandelowski, 2000). Data is typically analyzed using a variation of content analysis, whereby the findings come from the participants and existing knowledge rather than derived theoretically (Milne & Oberle, 2005; Neergaard et al., 2009; Sandelowski, 2010). Qualitative description entails that the researcher remains as close to the data as possible without over-interpretation of the data itself (Sandelowski, 2010). Qualitative description is particularly useful in forming descriptions of health services access with easily translatable practices for clinicians or policy makers (Sullivan-Boliyai et al., 2005).

3.3 Data Collection

Before any data could be collected, ethics approval was received by the McMaster

Research Ethics Board. The data was then collected in a series of steps in order to answer

the research question with usable and relevant information (Creswell, 2013). Data

collection started with locating a site or individual and followed a clockwise path as seen

is Figure 4. After locating several Ontario Early Year Centres (OEYC) in Hamilton and

Burlington, I created a rapport with the staff and users in order to more easily collect a

purposeful sample of mothers with premature newborns. I then proceeded to actively

collect data by conducting face-to-face interviews with women. Interviews were all

audio-recorded, while I wrote simultaneous notes of key observations. Where applicable,

field issues were dealt with prior to anonymizing and storing the data for confidentiality

and organizational purposes.

Figure 4 - Illustrative wheel of the cycle of data collection. Modified from Creswell (2013)

3.3.1 Sampling & Recruitment

The sampling techniques used were purposeful sampling and criterion sampling, through
which I recruited participants who fit the inclusion criteria. The initial inclusion criteria
for this study were English-speaking females, residing in the study area for the duration
of their pregnancy, and had a preterm baby within the last year. However, this sample
proved very difficult to obtain due to access and rapport barriers, so the decision was
made to include participants that met most, not necessarily all, of the criteria. As such, the
study design transitioned to more convenience sampling instead of criterion sampling. For
example, approximately half the participants did not have their child within the last year
as primarily expected, so the inclusion criteria was broadened to include women who had
their baby within 3 years of the time of interview. Given the constraints on time, money,
and effort, broadening the inclusion criteria was deemed more beneficial than the possible
recall bias that may affect the reported experiences of the mothers. The final sample
consisted of 13 mothers of preterm babies. Nine of the mothers were from Hamilton,
while 4 were from Burlington. There were an additional 2 key informants interviewed,
one from each of Hamilton and Burlington.

The recruiting efforts consisted of flyers, phone calls, emails, and predominantly
attending programs at OEYCs in multiple locations. In the original study design, making
connections to a gatekeeper in the public health community or specifically at a few
Hospital NICU sites would have provided direct access to the original purposeful sample,
though there were many barriers to this. The next best and recommended course of action

was to visit OEYCs because public health, NICUs, and family doctors all universally recommend that families and mothers use this free and supportive service. My sampling method assumed that the same women who utilized those above direct services (NICU, Public Health) were recommended and subsequently were using their community OEYC.

An unexpected barrier with recruiting the sample was that mothers of newborn infants were all *new mothers*. New mothers are exhausted, feel unsupported, feel drained, and feel isolated, which all likely contribute to staying home more (Barclay et al., 1997). This posed a difficulty in the initial identification of the targeted population since they were possibly not attending my sampling locations for me to approach them.

Gaining the trust of the participants is an extremely important consideration before recruitment (Baxter & Eyles, 1997). Firstly, this required formally meeting key informants ahead of time, and being introduced to program leaders via email before I showed up to any OEYC programming. Secondly, trust was gained by becoming a participant in various programs before attempting to recruit any mothers – some of which included mom-and-newborn sing-along groups (Mother Goose), and infant massage classes. Gaining trust in this way influenced an air of approachability towards me and established my respect for the participant's time and needs. However, building these relationships did cause difficulties due to the amount of time and effort spent in specific locations, which resulted in an opportunity cost at other locations, and even possibly affected my trustworthiness negatively at the other locations.

3.3.2 Semi-Structured Interviews

Interviews can be used in qualitative research to obtain information that is not easily quantified or understood from other research methods. Interviews used in qualitative research can take on many forms, but are particularly flexible in order to retrieve thick, rich descriptions from the given study population (Creswell, 2013). Interviews may be used to explore perceptions, to get deeper understandings and meanings, and to explore a hypothesis on a given topic (DiCicco-Bloom & Crabtree, 2006).

Data was collected through semi-structured interviews. Semi-structured interviews cover a specific set of overarching topics, but the structure still encourages the interviewees to take on tangents, to focus on areas that they want to, and to frame what they believe is the most important aspect of their experience (Bryman & Teevan, 2005). The interviews were conducted in a one-on-one, face-to-face format, meaning there was just one researcher – myself, and one interviewee at a given time. This decision was to maintain a comfortable, non-judgemental atmosphere during the interview, and to ensure that spontaneity, rapport, and personal observations were prioritized (Bryman & Teevan, 2005). I encouraged a conversational interview when participants were comfortable with it, and used probing questions and follow up responses (See responsive interview models like Rubin & Rubin, 2012).

The interviews were comprised of open-ended questions (Appendix D) concerning pregnancy and birth experience, behaviours while pregnant, and utilization of various services. Example questions were: *"Can you tell me any barriers to maintaining a healthy diet while you were pregnant?"* or *"Where were the first places you looked to in answering questions about your pregnancy?"* The interview guide was modeled with two overarching ideas in mind. The first idea was to address the individual experiences of and perceptions to the known risk factors of preterm birth, because these have previously been studied using quantitative and cause-effect approaches. Secondly, a focus on psychosocial and behavioural factors like exercise, advice seeking, and support were focused on, as these are likely very contextually and place driven. Lastly, the majority of the interviews were conducted at the OEYCs in either Hamilton or Burlington – sometimes during a group play hour, or directly before or afterward in the lobby of the building. Some mothers preferred to meet at a local coffee shop or library.

3.3.3 Key Informant Interviews

Key informants are primarily used as gatekeepers into groups of potential participants; they are extremely beneficial to get a lay of the land with the population being studied (Creswell, 2013). Key informants can also be used as a resource to troubleshoot recruitment and fieldwork concerns (Bryman & Teevan, 2005), and used to increase study credibility by providing multiple accounts of the topic being covered (Baxter & Eyles, 1997).

The key informants I interviewed were the gatekeepers in my recruitment strategy and the most knowledgeable on the users of their services. I conducted two key informant interviews with the directors of the main OEYC sites in both Hamilton and Burlington. Again, it would have been ideal to get an insider with Public Health or other direct access informants, but such is the research. Regardless, they understood the strengths and weaknesses of their operations and they each had a wealth of knowledge on the communities that they serviced. In these interviews, the types of questions I asked were: *"What is the demographic of users like here at this location?"* and *"Can you describe the process involved in registering or deciding to use this service as a community member?"*

3.3.4 Participant Observation

Participant observation in ethnographic research is a complete immersion of oneself into the lives of the participants (Creswell, 2013). However, I was not fully immersed like it would be expected in ethnographic research, but rather I took a backseat and conducted observations when most beneficial and ideal. At times I was acting as a participant, i.e., singing when participants sang, and observing from within the active group, and at other times I sat on the sidelines and watched mothers interact with each other. These instances are respectively referred to as 'participant as observer' and 'nonparticipant/observer as participant' (Creswell, 2013).

The fluidity of my role as a researcher in the OEYC locations was very dependent on the nature of the activity, the day, and the participants themselves. Some days I would start as

a nonparticipant and watch a group activity waiting for new moms to come in so that I could recruit them, and other times, I would be a full participant and follow along in the activities like the other users (without a newborn in my arms!) and try to recruit at the session's end. This allowed the mothers to know that I have an understanding for who they are and why they are there. Actively participating in activities such as Mother Goose sing-along or having snacks at the Check It Out Drop-Ins, contributed to a more trustworthy connection with the users and the program leaders. I was able to consider the kinds of interactions happening, the topics of conversation frequented, how the staff acted, and why some types of programs were the most popular. As recommended, many notes were taken in order to separate descriptions and reflections on my experiences as an observer (Angrosino, 2007). Much like in interpretive description, the observations are key in influencing interpretations of the data, but remain grounded in the literature of current knowledge and theories (Thorne et al., 2004).

3.4 Data Analysis

Thorne et al. (2004) compare data analysis to tasting a good wine, in that it is highly experiential, rather than technical. This sentiment was directed in the data analysis because I remained very close to the data, and essentially let it lead me in any direction. I organized the data without the help of computer software so that I could remain as close to the data as possible. The interviews were recorded and transcribed verbatim, followed by thematic analysis. Thematic analysis of the data is used in qualitative research to find emergent themes, which are characterizations of the meaning of the data (Fereday &

Muir-Cochrane, 2006; Crabtree & Miller, 1999) and are data derived, not literature or theoretically driven (Sandelowski, 2000). Interviews should be thoroughly read and listened to until emergent patterns, themes and codes are realized (Bryman & Teevan, 2005; Fereday & Muir-Cochrane, 2006; Crabtree & Miller, 1999). Codes are the smaller scale characterizations of the data, which later are amalgamated into larger themes (Creswell, 2013). The emergent themes were generated inductively, meaning the codes created were a direct result of what women said in their interview responses, as opposed to driven by *a priori* determinations (Crabtree & Miller, 1999).

Creswell (2013) recommends identifying 25-30 temporary codes in the interview data, complete with supportive quotes, before reducing/amalgamating them into a leaner list of 5-7 themes. Classifying my interview codes was very exhaustive and iterative by combining and reducing themes until the most reflective six were left.

3.5 Rigour

Qualitative research analysis is made explicitly rigorous through the use of evaluative criteria: credibility, transferability, dependability, and confirmability (Baxter & Eyles, 1997). The principles in each of these criteria enhance the degree of trustworthiness in a given study – essentially validating its findings and conclusions (Baxter & Eyles, 1997).

Credibility was addressed in this study by providing clear and true representations of participant experiences. Purposeful sampling of mothers of premature infants was used to

get an appropriate sample; observations and notes were taken to make authentic conclusions; and preliminary findings were emailed to the participants to allow for validation of content, otherwise known as member checking. Transferability in studies, akin to generalizability, ensures that others can understand the contextual dimensions of the conclusions made (Baxter & Eyles, 1997). My study is transferrable via the thick description of the data and the thorough outline of the design. Dependability addresses the reliability of the findings (Baxter & Eyles, 1997), which was done through triangulation; the use of participant quotations, and the contextual considerations of participants were defined to remove subjectivity (Baxter & Eyles, 1997; LeCompte & Goetz, 1982). Lastly, confirmability concerns the removal of personal biases and the provision of any information that affected the researcher's interpretations of the results – this is referred to as an audit trail (Baxter & Eyles, 1997). This study outlines changes that were made in design and I also outline in the ethics proposal that there are no conflicting interests and no personal connections.

3.6 Summary

A qualitative descriptive analysis was undertaken in order to answer the research question concerning the influences on women's perceptions of access. Interviews and observations were conducted with women who had experienced a preterm birth and were living within the HNHB LHIN. Data was thematically analyzed, and various strategies were used to ensure rigour.

4. Findings

The findings section provides a detailed overview of emergent themes from the interviews and observations and provides a window into the perceptions and experiences of mothers living in the HNHB LHIN. Thick description and quotes were used to convey the truest perceptions and experiences of the participants. There exist some overlapping themes in the questions asked and responses received from the participants. The themes discussed are: *1) prenatal preparedness; 2) working while pregnant; 3) delivery expectations; 4) place and space; 5) supports and resource attainment; and 6) attitudes and knowledge.*

4.1 Participant Similarities

Among the women interviewed, there were a few noticeable similarities that will be addressed first. As indicated, all women lived in either Hamilton or Burlington for the duration of their pregnancy and consequently fall within the HNHB LHIN. All women were above the age of 26 for their pregnancies, held college degrees at minimum, and every mother was in her first pregnancy – otherwise known as primiparity. Except for one (P3), all other participants had planned pregnancies. All thirteen women worked during their pregnancies. Although a few women were recommended by their doctors to end work early for resting purposes, most of the women worked until their labour week/day. Over half of these women had jobs with required standing, such as teaching or retail work.

4.2 Prenatal Preparedness

Two channels of preparedness were brought to attention: 1) the preparedness via

understood knowledge that the women had via their primary care provider, and 2) the

personal preparedness of attending prenatal classes.

4.2.1 Previous Knowledge

There were women who had multiple or common risk factors for having a premature

birth, but seemingly not prepared for that possibility. For example, there were two women

(P9 & P12) who had gestational diabetes but were not prepared for if and when they

delivered early. P12 had mentioned that she recognized she was an older mother (36 years

old), but the connection to gestational diabetes and premature labour was not addressed.

Consider P9's response after asking her primary care provider if she might deliver early:

> *P9 – "No, no actually. I saw my OBGYN the morning I had him for like my weekly*
> *checkup and I was like: 'I'm gonna have him early,' and she was like, 'no you're*
> *not' and I was like 'yes I am' and she was like 'I'll see you back next week' because*
> *she checked me and was like 'you're not ready' and I was like 'I'm gonna have my*
> *baby'… and my water broke that night."*

This response also illustrates a common thread that many of the women shared, which

was a feeling that they were going to deliver early, even when the care provider did not

anticipate it. One woman cleaned out her office desk on a whim the day she ended up

delivering; another woman told her husband to stay near his phone because she had a

feeling it would be soon. Overall there was a sense of calmness to the possibility of

delivering early in many women. This could be misinformed, or due to recall bias, but it was palpable in discussions with the mothers.

An example of a woman who did not feel she would deliver early was P1, who smoked once a day during her pregnancy. She remarked that she was *"oblivious"* to having her baby early. Other indications that women may not have been prepared, or rather received the respective information on having an early labour were a few women who said that they were happy about their baby coming early. For example, P3 had 5 risk factors for preterm birth, and said in response to a question about her feelings about not reaching term: *P3 – "Uhm, I was kinda glad, glad to get them out."* Having 5 risk factors and feeling glad to deliver early hints that although this woman is at risk for various complications, her happiness outweighed those risks, and/or she was simply misinformed about the risks.

The only women who expected a high likelihood of an early delivery were P2 and P9, both of whom had non-mainstream birth experiences. P2 birthed via In Vitro Fertilization (IVF), and P9 had Donor Insemination (DI). P9 had 7 identified risk factors for preterm birth, including carrying multiples and being over the age of 35. P2 said in response to her reactions/feelings to having a preterm birth:

> *P2 – "I probably had a lot of information that I needed...I was just really grateful to have made it to that gestation versus having like a baby at 24 weeks or a microbaby at 27 weeks."*

Information Flow – Preparatory Knowledge

There were a few instances where mothers had certain, incorrect information. For

example, when asking mothers about prenatal vitamins, one woman said:

> *P7 – "I didn't know that was a thing [prenatal vitamins], so no. And then I was reading the pills afterward and apparently you are supposed to take them after you conceive and like when you are breastfeeding, and I didn't do that afterward so…"*

It could be assumed that it is the doctor's role to underline the importance of prenatal

vitamins. But then again, most of the women were not prescribed a food diet or were

sometimes told in some way that standing didn't have anything to do with their early

delivery. P9's doctor told her in a response to a concern about not eating well enough:

"People in third world countries deliver healthy babies, so don't worry about it…You

probably have enough stores in your body." The perception a mother may have when

hearing *"don't worry about it"* to a legitimate concern must be very complex. In fact,

some mothers reported only gaining access to some information because they knew to ask

questions about it. This may be considered concerning if mothers never knew to ask those

questions, and further, if the mothers did not get important information. For example, P8

said she had to ask to find out what was wrong with her newborns when they were

throwing up so much in the beginning. As it turns out, they had hearing problems, a heart

murmur, and reflux issues, all directly related to her having given birth early. Moreover,

she was only told about how these issues were common for premature newborns four

months after birth. She further goes on to say:

> *P8 – "I just I wish there was a little more info saying you know, they are preterm, so these are some of the challenges that you might face, or these are the things that are normal to keep in the back of your mind."*

4.2.2 Attendance of Prenatal Classes

In large part, the majority of mothers took their prenatal vitamins and attended necessary appointments, but there was a noticeable aversion concerning women attending prenatal classes. Women reported some indication that they did not want to learn more about their pregnancies because they either did not want to know what all the possibilities were, or because they felt they already knew enough about pregnancy. Here are P5 and P9 who did not attend prenatal classes out of fear:

> *P5 – "I didn't go to the childbirth classes because I figured that they would probably scare me, I thought, they know what they're doing and I don't. They've got to do this all day everyday so they can just tell me what to do. I figured the less I know the better."*

P5 would rather rely on and trust in her primary care provider than to prepare personally. P9 reports she was self-aware and thought that preparing for the birth may not be very useful because essentially, stressing over it for 9 months would do her no good.

> *P9 – "I feel like every baby is individual and I didn't want to know anything about the labour because I dreaded it so much that I could like, if you tell me all the worst things are going to happen, I'm going to think all those worst things are going to happen to me, so I'd rather go in knowing nothing and then when those things happen you deal with them as they come – rather than stressing about them over 9 months."*

Another participant (P13) worked in the Neonatal ICU and felt that she was prepared for her baby and pregnancy. When asked if she attended prenatal classes, she said: *P13 – "Yeah I did the prenatal classes, for my husband, because I work with babies for a living, so…"* As was the case with P13, several mothers implied that they did not need prenatal care classes because they had worked with or had babies in the family. All three of P9,

P6, and P7, had never previously experienced being pregnant, yet they felt confident

because of their previous children-related experiences:

> *P9 – "Especially with the job that I have, like, I already know everything – well not everything – but I know what could happen and having a healthy baby is a miracle. Like, you know that most babies are that way, but that's not the case, you just don't, you know, they assume that they are going to have a healthy baby and that's very rare."*

> *P6 – "I didn't go to any. I have a very big background in kids, and I worked in daycare, I felt very prepared, I didn't really feel like I needed it, so yeah… I worked – I've been in the field with kids for like ten years, so I felt fairly confident that I could handle it."*

> *P7 – "All my cousins are younger than me, so I mean I grew up changing diapers."*

Regardless of the reasons behind not attending, many women did not attend prenatal

classes, and still feel like they did not need to have attended those classes.

Another reason that prenatal classes were not attended was because of poor timing and

scheduling issues. The schedules of prenatal classes and various activities in the

community were not compatible with the hours and occupations of the mothers

interviewed. For example, P1 barely had any time for herself, *P1 – "I was working,*

standing for about 10-15 hours up until 2 days before," let alone prenatal classes or other

activities. P4 worked long hours in Toronto, but lived in Hamilton and had too many

things to do to fit in prenatal classes, *P4 – "No, because I didn't have time… too many*

things." In addition to poor schedules, P4 noticed that there were additional barriers to

booking or registering for various activities:

> *P4 – "I tried… I called the city, there was one where you call, I don't even know where it was, I think it was at one of the hospitals but they never got me in, and then they said you could do it online…"*

Not only did many women not attend the prenatal classes due to scheduling issues and availability, but women who planned to attend classes closer to their due date missed out *because* of their premature labour. P4, P8, P10, and P12 all prioritized prenatal classes for later in their pregnancy, and ultimately did not get to attend them due to the unexpected early births, see P10:

> *P10 – "Well, we attempted to do the prenatal classes, uhm, but by the time we'd get into one – so we managed to get just two prenatal classes, but then she arrived and that was that."*

P11 recognized that she should have attended the prenatal classes earlier, *P11 – "It was literally like a week later I had my baby, so I would say possibly it could be taken a little earlier."* It was unclear whether this was her health care provider's recommendation, the classes were full earlier on (as was reported by the other mothers), or if it was due to scheduling conflicts or lack of options throughout her pregnancy.

Besides this issue is the common thread that even when mothers attended prenatal classes, mothers did not benefit from them. P11's account of her prenatal class attendance was described as *useless* at first:

> *P11 – "We did the Halton Region Prenatal Health Classes – we did the crash course, but that was literally like, useless… no no no, it wasn't useless, like I already knew most of it, like it was still useful, but…"*

Women described that the prenatal classes were not engaging, were lacking, information was outdated, and generally not reflective of the actual experience.

> *P8 – "So I did a prenatal class, it was an online class, with the city. There's two in-class sessions and the rest was online, and it was not entirely worth my money to go to. I don't know whether I had an instructor that wasn't very engaging or what, but I didn't get much out of it… …It wasn't very realistic, and the video that they show*

you they took in Christmas lights to the hospital and decorated it all up and they had the preprogrammed iPod and had all this nice music, a ball… it just seemed not what the average person would do… and that wasn't just my opinion… that was everybody else's opinion too and it just seemed like they were a little outdated."

P10 explicitly discussed also how the instructions that she learned in her classes were not at all like what she experienced in labour.

P10 – "…I was like, 'err, I was in North Bay and uhm my water's broke and four and half hours later she was here – so I didn't get to watch a movie, or have a massage,' And then they were saying like, 'when you are in labour, you can sort of walk around and find a position that's comfortable for you.' Maybe it's because I was early, but they had me lying flat with the monitors on and I wasn't allowed to sit up or move around or anything…"

This woman did her prenatal class in Burlington, and ended up giving birth in North Bay.

Further, when women who did attend prenatal classes were asked if anything outside of an expectedly normal birth experience was mentioned, they replied negatively. When asked if labour before full-term gestation was brought up, P10 responded: *P10 – "There was nothing at all mentioned [in prenatal classes]… that was really not helpful at all."*
P11 provided a similar answer:

P11 – "…I don't remember it being mentioned at all actually [preterm labour], like I know after 37 weeks you're good to go, and that was mentioned, but they didn't talk about who doesn't make it to 37 weeks"

It seems as though no preterm labour expectations were addressed, but rather the classes wholly focused on what it will be like for an average, possibly 'normal' birth. When referring to a normal birth, it is meant that the baby will be born vaginally, with little-to-no doctor interventions. Today, typical accepted interventions in normal births include giving medication to activate labour, monitoring the baby's heart rate, and administering

pain relief (SOGC, 2016). Regardless, whatever the average birth experience is, these women did not relate to, nor were they given the chance.

4.3 Working While Pregnant

The women shared a habit throughout the span of pregnancy, which may not sound uncommon – working regular to long hours and staying home in free time. Work was a common theme that elaborated specifically on the sub themes of accessibility, scheduling, loneliness, and exhaustion. These will be discussed altogether in a narrative format, as they all intersect quite often.

All of the women interviewed maintained a full-time occupation. Some of the various work positions included department store worker, teacher, veterinary nurse, car dealership clerk, physiotherapist, researcher, and dog walker. Women often liked their jobs, but identified work as being problematic in some way and often connected it to time needs. To illustrate the work demands of many of these women, see P7:

> *P7 – "I worked about 40 hours a week! ...My husband leaves for work at 9[pm] and I get home at like 6 [pm], so we have no time to even clean and eat." ... "I worked that week [went into labour]. Yeah, no idea! I had no reason to take an early mat-leave."*

Women's work contributed to competing demands right up until birth for many women. P1 said she worked *"right up until 2 days before."*

With the pregnant women working such long and consistent hours, there was less room for socializing or regular past times. In asking women about finding local supportive

activities or friends, some indicated that it was pretty difficult and inaccessible because of their work schedules. This was because of both personal and external scheduling issues. The women mostly worked full time, regular hours, but even so, the schedules of friends or external mom-type groups seemed to not match up well with theirs. P7's late schedule limited her availability, which made her quite *"bored"* as she said more than once. Also, see P8, whose preferred support group met during her work time hours and so she missed out entirely:

> *P8 – "One of the big – you were asking about roadblocks/barriers – well I was still working, so there were, there was, like something run by the city where you could get together with like moms and if you came before you had the baby then you could continue for like 6 months afterwards…because I was working more often in the day, I couldn't attend them."*

P8 even goes on to say that her need to attend appointments was getting in the way of her work. Taking sick days and vacation days for appointments makes for a very stressful and jam-packed schedule: *P8 - "I even, I had a hard time because I had so many ultrasounds and I couldn't take them all as sick days because they would start docking you…"*

Making time for doctor's appointment and compromising their work life was a clear struggle for the pregnant women in the workforce. Work can then be seen as a barrier to finding supportive systems, but also for accessing basic health care needs. P8 further explained barriers to accessing her doctor's appointments in respect to time:

> *P8 – "Work and time – because I went to Mac and it was over an hour to wait for every ultrasound, and then I'd have to go see my OB afterward, and quite often it would be a half hour wait there…"*

Again, women often expressed the difficulty in juggling work in addition to care and

social needs – as one might expect, being pregnant in its own right is quite exhausting. P4

rode the train to work, which was over an hour commute, just so that she could sleep in

transit, even though she could drive. Further, P9 needed to nap every day to feel

somewhat normal:

> *P9 – "It was hard… like the days that I worked I was exhausted… I got an hour and a half break at work, so I usually napped. Every day. And I just ate at my desk and then I napped every day, so it helped – to be honest if I didn't get that nap, I wouldn't have survived, because I was exhausted, but I mean other than that, it was okay."*

It was evident that pregnancy was subsequently lonely for some mothers, and that work

and schedules were a big barrier to overcoming the lonely times and need for support.

This was in part due to the exhaustion. Here is P10's response after asking her about

friends or activities that she was involved in:

> *P10 – "Not so much, 'cause we were all at work, and I was crazy busy at work doing sort of long crazy hours and things, so yeah, not so much. I think pregnancy was more lonely than it has been from when she came home… so that was harder but still, I'd have the two neighbours who were pregnant at the time that you could send a text...but they were at work, I was at work, so yeah, it wasn't easy. It was a little harder and a little rougher."*

This sentiment surrounding the idea of loneliness and work scheduling was shared by

some of the other women. On the other hand, some women did benefit from their place of

employment because they saw it as a support system of its own. In this case, P4's mother,

as well as her work environment, were facilitators for social support: *P4 – "My mom was*

pretty good, and I guess even people at work were good. We all used to bring in stuff for

each other and share." Further, P6 identified a pattern of support at her work:

P6 – "I work with all women who, we go through like waves of pregnancies and weddings so there's always someone there to talk to." The work support system was extremely beneficial, but it was wholly dependent on the population of people working at your place of employment, and also on the structure of the working environment. Actually, more than a couple mothers indicated how nice their bosses were, in letting them take naps at work, or in making special arrangements that made their jobs easier throughout the day, such as extra seated time.

4.4 Delivery Expectations

Of the 13 interviewed women who had premature babies, every one had some form of hospital intervention, and each one experienced a change in their birth plan.

4.4.1 Change in Birth Plan

Women for the most part did not have their birth experience go according to plan, meaning that at minimum, their expectations were not met. For instance, they may have wanted to have their baby without pain medication or have a family member present, but missed the opportunity due to an unexpected delivery. P13 did not initially want any pain medication, but since her doctors wanted to induce her, she had to get an epidural from the pain anyway:

> *P13 – "I wasn't overly happy about that [being induced] because it meant more pain, so… I got an epidural, I wasn't planning on having an epidural, but I had one."*

A change in birth plan can sometimes be traumatic, sad, and confusing for a mother. For example, P5 recounted being stressed out and not ready for what was about to come, especially because she was one of the mothers that had few risk factors and seemed to be very involved in her pregnancy.

> *P5 – "So they wanted to deliver him as soon as possible because they decided he was a healthy weight and that it was safer for him - so I wasn't ready, I just wasn't ready. I went into the hospital for a check-up and it was that night, so I was like 'Okay!' So it was a little bit stressful!"*

P11 was disappointed about the day-of plan itself. When asked about her labour, she explains how she imagined and planned for it, and then describes how it actually was:

> *P11 – "That didn't go as planned. Yeah, my birth plan was like open-minded about the epidural, my husband there, skin-to-skin right after, delayed cord clamping… but by the time he was born, my sister was still there and she's a medical doctor, my husband was there, the doctor was there, two nurses and two others, a pediatrician and a respiratory therapist, and then we didn't get skin-to-skin – 'you got brushed off' [she says to her son]."*

In this scenario, it seems like there was an excellent array of medical attention, but in the mother's perspective, it was not as intimate as she hoped it would be. It seemed as though mothers felt after-the-fact that there may have been a possibility to get more of a say in the birth process given their comments. P6 says that she *'"felt jipped"* after having to have a C-section and described it as the "*worst part of everything*". However, regardless of feeling disappointed or jipped, there were a few mothers who recognized that all they needed in the end was a healthy baby.

> *P8 – "Yes I planned a natural birth, I was pretty disappointed because I really wanted to try natural… they were facing down and they were really tiny so she thought they can't survive a vaginal birth, so yeah… To be honest I rather they come out healthy, and the C-section wasn't as bad as I was expecting… Yeah I was disappointed that I only had two days notice, so those two days were pretty hard, but I'd do it again."*

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Some women were better prepared for the possibility if their baby came early because of what had previously happened to their friends. P4 recounted feeling *"not surprised"* about it because the women at work were all having early pregnancies.

4.4.2 Interventions

In tandem with changes to a woman's birth plan was an increase in medical interventions. There was a pattern among nearly all the women concerning hospital interventions. As would be expected in a population that have multiple risk factors for preterm births, and who consequently did have preterm births, hospital interventions can somewhat be anticipated. For instance, at least five of the women had unplanned, emergency C-sections, at least three of the women had to start antibiotics because their strep B results were not in yet, and a number of other interventions were identified such as forceps delivery, vacuum delivery, lengthy NICU stays, and steroid shots.

Many of the women did not anticipate or plan for any of these interventions. Perhaps they were introduced to them in their PCP prenatal care appointments, though it seemed that the women largely were not expectant of the interventions. In fact most of them did not realize it may be a cause for concern until it was happening in the moment. Also, it was noticed that when asking women if they feel they had a normal pregnancy, the majority of them said something to the tune of (P10) *"up until that point it was perfectly normal."* Additionally, women were found to explain away their feelings and experiences like this:

> *P11 – "Other than the diabetes aspect… I had some nausea, but nothing crazy, tired, hungry, but other than that nothing crazy. I had no other indication that he was going to come early."*

First, P11 in particular had over 5 risk factors for preterm birth, so it is odd that she had no indication. Second, it sounds like women either think that they have a normal pregnancy or the alternative is that 'crazy' things happen and there is no in between – black or white. Perhaps the definition of normal pregnancy is not communicated to women from their health care providers.

There were also unexpected newborn concerns that were attributed to giving birth preterm. Some women mentioned the types of problems that their preemies had coming home from the hospital. For example, P4's baby was very colicky, P6's baby was underdeveloped physically, P2's baby developed an arrhythmia, P10's baby had undeveloped muscles, and P8's baby had developmental delays and hearing difficulties. These issues do not go away overnight; take P6 as an example: *P6 –"But she's almost ten months and she's not crawling or anything yet."* There is a variety of potential issues that premature babies are affected by. Not only is this difficult on the parents, it is a burden on the health care system, and has many delayed affects.

4.5 Place & Space

Place and space are considered part and parcel of understanding health geography contexts (Kearns & Joseph, 1993). It was found that women sometimes made decisions based on the location, schedule, and type of resource/service offered. The time and space

distribution of women's prenatal classes, hospital, and various activities (like mom-and-tots clubs) made an impact on women's perceptions of access and influenced their choices.

4.5.1 Space

Locational & Time Influence

There were not many references to space in the participant interviews, but it was noticed that constraints on time in terms of location of work, hospital, and various activities influenced how and where women spent their time while pregnant. Overall, the participants were often restricted to certain areas because of their work or home address. Some transport discussion came up with deciding which hospital is more desirable and in decisions about whether or not to attend in-person prenatal classes or not. For example, when talking about which hospital one mom used for her birth, P10 said:

> *P10 – "No, I was going to deliver at Oakville Trafalgar, just because it's two minutes from my work in Oakville… Because I know sometimes work can get crazy, but then driving just two minutes down the road to my appointment is okay"*

She later discussed how it would be less manageable if she were to choose someplace further away. In either case, this does not seem to often matter so much for women like P10, who were not near their hospital when they went into labour.

There were two women who worked in Toronto that were similarly influenced by constraints of travel time. P4 indicated that she worked far away and that it was more difficult to access programs that she was interested in. She further expressed interest in

more OEYC location(s) on the Hamilton Mountain, where she lives: *P4 – "The service [OEYC] is really good, I wish there was one on the mountain…"* It seems that her, along with some other mothers, were all willing to travel longer distances to access postnatal programs such as those offered at the various OEYCs.

Additionally, when it comes to absolute location of activities, P2 mentioned that "*getting around"* to programs was an issue, and another mother, P3, mentioned that the services she was interested in for her sons were *"scattered."* For P3, the locations being scattered played a role in program uptake of various community activities such as music lessons. Conversely, she later said, *"Geography didn't affect us much, other than getting around."*

A couple of women divulged that weather, parking, and driving were annoyances to leaving the house, or influential in attending appointments or services: *P4 – "Yeah it was snowing, that was pretty much it – the weather. It was horrible, there's no parking at the places, I fell a few times."* These issues lend to why others may be discouraged to attend certain activities, be it directly health related or not. P9 mentioned that she was discouraged from taking kids out in the winter altogether. Two of the mothers (P5 and P7) indicated that they recognize the need for certain resources (car, money, accommodating employers, etc.), and how they can be a deterrent to attending various appointments or social opportunities for others: *P5 – "I can see how there would be [challenges]. I drove and paid for parking and it was no big deal, but I can see how it would be if you didn't have resources."* P7 alludes to the idea of driving being an issue for women who are

pregnant and trying to get to places like their appointments: *P7 – "Uhm, I didn't drive yet but my husband drove, he wanted to attend everything anyways, not really a big deal."* The majority of women could drive and did drive their own vehicles, so it was initially not noticed in this group of women that transportation was a big hindrance.

Burlington-Hamilton Usage Pattern

A pattern was noticed in the distribution of program users in the LHIN. It was evident that women from Burlington frequently used the Hamilton OEYC sites. In personally recruiting at the Hamilton sites, often when asking women if they were from Hamilton, they would say they were from Burlington. At the Burlington sites on the other hand, I never ran into women from outside of Burlington. Additionally, the user population was different between the two OEYC locations. It was both observed and confirmed by the KIs that Hamilton locations had a large demographic of grandparents, fathers, siblings, and care providers other than birth parents; whereas at Burlington it was primarily birth mothers in attendance. Both OEYCs were universal and were open to whoever wants to come to them. KI1 from Hamilton indicated that this is a strength of the programming, because it means they never have to turn people away, making it a more inclusive and accessible service.

Moreover, when considering prenatal classes and programming locations for pregnant women, as opposed to OEYC-type activities for postnatal women, there was a visibly similar geographic usage pattern.
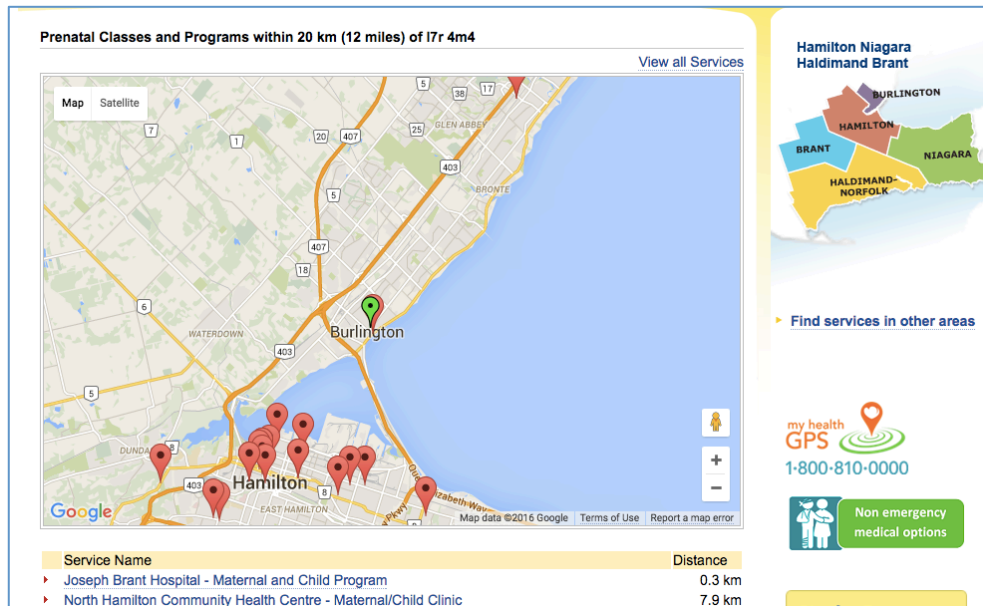
Figure 5 - Hamilton-Burlington prenatal class locations for Spring 2016 (HNHB Healthline, 2016)

The screen capture above illustrates the locations of prenatal education resource offerings on a given date in Spring 2016. Notice that for Burlington, there was only one local site to participate in prenatal classes, and that the next closest class is 7.9km away, and located in Hamilton.

4.5.2 Place and Social Contexts

Place is more subjective than space in that it is largely the outcome of the interplay of location and human experience.

Schedules

Both the absolute geometric location of some services, and the offered schedules, were

obstructions to mothers. When P11 was asked about participating in activities catered to

her needs as a pregnant woman (e.g., prenatal classes or prenatal yoga), she indicated that

she did not want to pay for them, and then goes on to say: *P11 – "I looked into it, but my*

schedule... I work Saturday mornings and I work evenings and a lot of the stuff wasn't

really available with my schedule" The scheduling issue came up with almost half of the

women, indicating that the times of prenatal classes or OEYC programming were not

conducive to their working schedule. Schedules of prenatal care appointments during

work hours were also a hindrance to mothers who said they were very difficult to attend.

Few participants alluded to there not being enough sick days or vacation days at their

workplaces in order to make all their appointments. However, there was a common thread

of having understanding bosses who were lenient with their pregnancy needs.

Nevertheless, women were stressed about making it to their appointments while not

missing work.

Affordability

Earlier, it was noted that there were financial barriers to accessing programs and prenatal

care. Prenatal classes specifically are not always free. Cost was brought up a number of

times when mothers were considering which prenatal class to attend – if they attended

any at all. P8 reports on her experiences, echoing a few of the other mothers'

deliberations in choosing whether to do prenatal classes.

> *P8 – "Halton offers one which is multiples, which is free, but it's all in-class, and I*
> *didn't find out about it until after I'd had the boys. So I sorta struggled because I*

> *thought there was more prenatal classes offered and that was the only one that I found and… it was okay, but… It was like 30 bucks. It was a hundred and something if I wanted to go to the classes…"*

She continues on about how she was a single mother, and how she did not want to go to the classes to breath and practice all by herself.

The concern for cost was not just reflected on prenatal classes, but on any activities in the city. A couple of mothers mentioned the difficulty in finding free social services, but when they were free, mothers were more inclined to go (although reported experiences were mostly of postnatal services). When asked about the ease of finding resources while pregnant, P8 comments how she wishes that women were equipped with a *"list of free resources where you live."* However, just because a program was free, it did not always mean it was accessible or accommodating. P4 elaborated on how registration was required for some programs: *P4 – "There is a service at Mohawk College, but you have to register – you have to register for everything and if you don't register the day that it opens, it's full."* Overall, the pertinent accessibility concerns that were not directly related to cost were programming being fully registered or no longer offered, and that prenatal classes were too far away or charged more to attend in-person.

4.6 Supports and Resource Attainment

Supportive resources help a mother through her pregnancy. Some supportive resources are fun activities serving as stress relievers, informative support groups, helpful care providers, and trustworthy people to talk to and ask questions of. It was found that

women frequently and actively sought out supportive resources, information, or services online. As we will see, this was predominantly happening while mothers were pregnant, and less so after their babies were born. Mothers also used their friends, families, and books for support, but I will present these separate from online support, as they have different implications.

4.6.1 Online Support

The Internet is a place mothers can do things like find out what is happening in their communities, ask questions, get instantaneous answers, and make connections. When mothers were asked about where they went to get answers to health questions during pregnancy, a few women mentioned going online or, as P1 described, searching "*Dr. Google*". P10 also used Google, though recognized that it is not the most trustworthy to do: *P10 – "Yeah I always Google things even though then [I] decide that I really shouldn't, there's lots of bad things, I would say 'Mm no thank you'."* In addition to using Google to get a quick answer, moms used other online platforms to find people who could help answer their questions and to also create personal connections. P6 used an online support group she found to learn more about a rare condition she developed throughout her pregnancy.

Further, nine of the women explicitly indicated that they went online to find activities and make connections for themselves and their newborns both before and after pregnancy. Moms commonly sought out resources such as Facebook groups, mobile phone apps,

peer-support programs, and generally any pregnancy-related support system. Of the online sources they used, Facebook seemed to be quite popular. When asked about advice, P8 elaborated on the heaps of information and support that she has gained from Facebook groups:

> *P8 – "There's a couple of Facebook groups that I joined…and one of the girls I work with…so she suggested I join this group, so I did, then it turned into a bunch of other groups. And they've been an amazing help since I had the babies… …There's like a breastfeeding group, there's a tandem baby group that I joined and just all kinds of yeah… it's – and that's something that I can do like when I was pregnant I didn't want to really get up and go out and I just wanted to sit on the couch with the computer on my lap and talk to people on there right."*

P11 also found many useful groups from the first Facebook mom-to-mom group she joined, which served as a platform to sell and trade clothes between new moms. From this group, she joined 'Burlington Baby Mammas' and also joined a mom-book club. P12 found both a breastfeeding support group through Facebook, and also a mom-to-mom peer counsellor. P7 created her own Facebook group as a way to stay connected with her family and keep them informed about her newborn. She wrote posts and put up photos, and since her preemie had many complications, she found it was a good platform to share information quickly and conveniently to her loved ones. Some other online supports that mothers accessed were 'Momstown' (P13), a couple unnamed support groups online (P5, P12), and even found support in the form of online gaming (P7).

Mothers sought out information that would help them better understand their pregnancy and newborns. For example, two women joined a breastfeeding group to make connections and share information regarding that stage. This can also be seen by P10 and

P11, who talked about how they downloaded a mobile app that allowed them to better follow their pregnancies remotely:

> *P10 – "The whole week by week we did on our iPads sort of – the pregnancy app – so every week it'd tell you what fruit they were as big as, what sort of [thing] they were growing at the time and things like that…"*

P11, a highly educated mother from Burlington who worked a lot, talked about why having the mobile app was so useful:

> *P11 – "The Baby Centre app was actually kind of a nice little – just because everybody is at the same stage as you and it's literally thousands of people on it, right, it's all across Canada, so like, yeah you're having morning sickness but none of your other friends have morning sickness, but there's like two hundred people on there that also have morning sickness."*

She went on to say explain the app's features, such as how the app was due-date specific and provided informative videos. The app helps connect hundreds of moms going through the same thing, regardless of geographic region or other demographics.

The app and the Facebook groups were helpful online resources for the mothers, but other resources worth mentioning that can be functionally grouped with online resources are the telephone services, Telehealth and Motherisk. Like online resources, telephone services are free, available from home, and serve similar purposes to some of the groups that mothers were a part of. For example, P11 sought out Motherisk for information regarding exercising while pregnant, all while never leaving her house or paying extra.

The Internet and telephone services can be seen as a channel for finding information, such as program schedules, times for children's drop-ins, and news. For example, women often

first used Google to locate programs or a phone number, then made the connection on

their own. However, this task was not always the easiest; when asked if it was easy to

find information online, P6 reports her difficulties in locating a phone number and how

some places did not have great websites:

> P6 – *"It was because I've had prior knowledge of it, but I think if I was a mom without any sort of... connection to it, I wouldn't have been able to find it as easy, cause I did go online to look and it was really difficult to find specific information without having to call, which isn't always the easiest with a baby... ...So yeah, definitely finding it online if you – cause that's where you're going to go right? You're not going to look in the phonebook [laughs]."*

She mentioned how some websites, such as for daycares, were not regulated and therefore

casting uncertainty on whether the information available was still useful, relevant, and

accurate. P6 found a few daycares that she was interested in, but after inquiring, they said

'Sorry, we don't run anymore.' Prenatal classes in the community could be thought of

like this as well, given the confusion mothers had about the availability, acceptability, and

accessibility of them. Further, if a phone number was found and a successful connection

was made to a program a mother was interested in, she might still reach barriers before

accessing the resource. For example, see P4's barriers in contacting the OEYC in East

Hamilton:

> P4 – *"I tried to sign up [for OEYC activities] like so many times but they never called me back…...I tried to get into an infant massage class for months because he was really colicky at the beginning and gassy since he was like a couple weeks old I tried to get him in. I never got him in, they fill up quick. And now daycare, I don't think I'm gonna get it in time."*

This particular instance only came up once, but it does bring up a few issues. What P4's

experiences suggest is that there were not enough resources for pregnant women and

newborns in the city. Both KI1 and KI2 confirmed that more resources (money and

space) would be extremely beneficial to program improvements. Furthermore, not all women knew how to access resources that would benefit them. A few women noted that although they knew where to look for resources, or although they had no problems finding a service online or elsewhere, they recognized the difficulties that *others* may have doing the same thing. This may explain the few women who did not mention accessing these services, as they may not have known where to look or if supportive resources were even available in their communities.

4.6.2 Word of Mouth

Word of mouth is a common way that moms learned of resources in the community, such as various moms groups and daycare. Word of mouth considers all cases where women learn of opportunities for the betterment of their pregnancy from a friend, family member, coworker, etc. For example, when P5 was asked about where she looked for certain resources, she said: *P5 – "I'm an ECE [Early Childhood Educator] so I uhm, I'm connected, I got people."* Similarly, P2 sought out a specific program online that her sister recommended, and later mentioned that she found childcare through *"word of mouth and friends."* P6 also found childcare through personal connections, and P8 found postnatal activities and resources in the community through work connections:

> *P6 – "I actually got really lucky… one of the girls that I'm friends with signed up her little guy up there [at a daycare she wants into] and so there was a space… so I went and I really liked it… …it's definitely not that easy for most people"*

> *P8 – "Right, post-baby I think it was pretty easy to do, but I think that's because I teach as well and so I knew a lot of the supports that were in place for that… I'm gonna say pre-baby I had no idea of what was out there."*

Both women indicated that they felt it was not very easy to find prenatal resources in the community without connections, which they both had. Regardless, getting support from family, friends, and books – next to the most frequented supporter, their primary care provider (for health related questions), was very common among nearly all of the women.

When mothers did not have access to word of mouth resources or did not show interest in them, they did show a preference for support from family members, friends, and coworkers. P3 and P6 shared explicitly similar sentiments to P5 who traded tips and experiences that other pregnant mothers had: *P5 – "Well, we have a cousin that's only like 9 days younger than him so we kind of hung out together and were kinda trading tips and whatnot."* A common thread was that women found or befriended other women (family or not) who were pregnant at the same time, to ask questions to and to share resources with. P13 was an example of a mom who, despite not being interested in attending prenatal classes or participating in activities while pregnant, had a support system of pregnant women: *P13 – "I had friends that were pregnant at the same time as me, I don't think we got together to do prenatal activities, haha."*

There was one woman (P1) who had five risk factors for preterm birth, inclusive of smoking and being overweight, who was disinterested in both finding online resources and meeting other mothers. However, this was not necessarily very representative of the group. When asked about if she participated in prenatal classes or got together with any other soon-to-be moms, her response was *"Hells to the no."* Regardless, there are

countless benefits of having a support system while pregnant, and groups in the

community seemed to be a good place to start for a few of the women who did not have

friends at the same stage in their life, or who were bored. For example, P3 also joined a

group to be with women who were also experiencing a multiple pregnancy:

> P3 – *"I joined a moms of multiples group, probably five months in …That's a support group made up of all the moms in the Ham-Burl-Oakville area whose had twins or triplets."*

Although there were examples of mothers finding support in some way or another, it was

found that mothers reached out more for support after their births. P8 got involved in the

community and various activities on a daily basis after her twins were born, and did

nearly nothing but work before they came:

> P8 – *"We go to a baby-wearing dance class. So I wear them and we do dance lessons, which is kinda fun cause I wear them and then I meet other moms… but yeah, we've been – we have something on every day of the week so far, so it's kind of nice to get out."*

Recall earlier she said, "*…Pre-baby I had no idea of what was out there."* She shared

how she wished there were recommendations to get involved for women who are

pregnant and how she learned of a Hamilton resource from her mother:

> P8 – *"My mom actually gave me even the link for the Hamilton – but she works for the city of Hamilton so she would know… Like I didn't. I wish they could give you something like when you go into the OB, or you go into the ultrasound, like if there was stuff there and say 'Oh I wish I could do this,' cause everyone has to go in for their ultrasounds. If you could have a list of free resources where you live… or just like, 'Here are some options of what you could do, or here are some groups that you could be in'."*

A few other mothers shared a similar sentiment, but were motivated more by them not

knowing or not specifically searching online for anything to do while pregnant – a

combination of online accessibility and knowledge of options.

4.7 Attitudes and Knowledge

4.7.1 Attitudes and Autonomy

Women's attitudes and autonomy throughout their pregnancies were illustrated through

the language that they used when recounting memories or experiences, and in the

expectations that they had of themselves and of health care providers. Women's attitudes

suggest many of them lacked the desired knowledge about their pregnancy. The language

and attitudes that indicate a lack of knowledge were evident from comments stemming

from at least one of hesitation, and/or misunderstanding. For example, P7 seemed

confused at the time of her pregnancy in the midst of a number of tests, as she said:

> *P7 – "They sent me to St. Joes and sent me downstairs to get a stress test, no one*
> *told me what was going to happen… there was an on-call doctor, interns, coming*
> *and going… they ended up sending me home after the stress test. I went to the*
> *McMaster Maternity Centre and so the doctor on call there went over the*
> *ultrasounds and said they shouldn't have sent you home, go to McMaster, and then*
> *McMaster didn't let me leave…"*

During arguably the most stressful time of her pregnancy, no one told her what was

happening and no one *"let her leave."* The word choices evoked a negative experience. In

a similar vein, P10 recounted how her prenatal class instructor told her what a normal

birth experience would be like, and further spoke about how she did not get to do those

very things:

> *P10 – "So I didn't get to watch a movie or have a massage, and then they [prenatal*
> *class instructor] were saying like, 'when you're in labour, you can sort of walk*
> *around and find a position that's comfortable for you,' maybe it's because I was*
> *early, but they had me lying flat with the monitors on and I wasn't allowed to sit up*
> *or move around or anything."*

Again, there's a notion of specifically *allowing* pregnant women to do something. It is unclear where this attitude originates from and what it is attributable to. Here it seems as though she was not allowed to do the things she was specifically told in her prenatal classes that she could do, and she was not given any explanation for the discrepancy. Consider also the women who were induced without much preparation or knowledge. P12 thought she had no voice in her birthing experience:

> *P12 – "Because he was preterm I didn't have my strep B results back, so I had to go on antibiotics just in case, and then they – because he was preterm – they didn't want to wait and see if I went into labour naturally so they induced me."*

She further explained her difficult, long birth experience, but first recounted her non-committal epidural choice:

> *P12 – "So then they asked if I wanted an epidural for pain management and I said 'sure, it's going to be a long time, might as well,' so they gave that to me at about 1:30-2:00 o'clock in the morning hoping I would sleep…"*

The mothers often did not know of their capabilities as a pregnant woman, and of their autonomy over their birth experience. One woman (P9) had to convince her doctor that she needed to push because she knew her body's limits to exhaustion, and was met with resistance and a poor attitude from the doctor.

> *P9 – "I know what my body can take and I'm done – so if you don't get him out of me soon you're going to have to cut him out because I can't physically do it anymore, like I was exhausted. And I just was like, done, so she was like 'well, you're going to have to push for hours' – like just I have to start because if I don't then I can't take it, and he was there an hour later… they were like 'fine, you can push if you want to', ya so they weren't nice and it wasn't an enjoyable experience, like I wouldn't have a baby there again, like on the floor [St. Joes] it was fantastic, the nurses were great, but for the delivery, they were horrible."*

P9's recount illustrates the culture of childbirth in hospitals as a push-and-pull between the health care provider and the woman. The health care provider in this scenario might

not have considered the mother's opinions, knowledge, wants, or needs. On the other hand, women can have an attitude of trust and submission to their doctors. P11 talked to her doctor a lot in her pregnancy and makes a connection to having a first child and having less overall knowledge by saying: *"It was my first baby, how was I supposed to know."*

4.7.2 Informed Care & Decision-Making

Among the participants, there was a noticeable lack of informed care or active decision-making when it came to pregnancy and the birthing experience. For instance, P8 could have been better informed about the expectations of premature newborn characteristics when she found out more about the delays her newborn was experiencing.

> *P8 – "Even at Mac where they have phenomenal care, there wasn't a lot of information given to me on the difference between having a preemie and a normal term baby – they just said 'oh yeah, you know they're preemies' or whatever, but I didn't know that their ears are more sensitive, or you know even like in terms of weight gain or of like any of the developmental milestones, they are a month behind…"*

The health care provider told P8 that her newborn was a preemie. In this instance, it is unclear whether the health care provider implied that P8 should learn about it by herself, or that it is not important and that she should not be worried. Instances like this feed the confusion around what mothers are expected to know. However, there were examples of mothers showing interest to be more involved in health care decision-making. One mother, who was used to the care in England, expressed her distain for the differences in care between England and Canada:

> *P10 – "In England, they've got clinics where you can just walk in, ask questions, and get them weighed, but here, you can't just walk in anywhere and get them weighed, so my mum's like 'When's she gonna get weighed?' 'Next appointment – three months time.' So initially it was… [shakes head]"*

Learning about your newborn, and here, particularly being informed about healthy weight gain seemed to be difficult for some of the mothers. KI2 even mentioned how many Burlington moms wanted access to weight scales and public health nurse assistance at the OEYCs (they used to have this as a drop-in service). Similarly, P8 wanted to know why she could not exercise through her pregnancy when she felt healthy otherwise, especially when she always exercised before pregnancy.

> *P8 – "If anything she [her physician] really discouraged me from exercising, and uhm the next one was like, 'oh but you have twins, you can't be doing that.' And I'm like 'Why? I'm healthy'"*

It seems as though she did not get a straight or informative answer for why she should not be exercising – just a negative response. P11 was also curious about exercise restrictions while pregnant and asked her doctor. In P11's opinion, her doctor provided an *"old-school"* recommendation of how much to exercise while pregnant, which led her to contact Motherrisk to find out more accurate information on her own. Mothers, then, are willing to seek information on topics important to them in order to help them remain informed.

Pregnant women typically plan for their birth experience. However, there were times when health care providers or friends were discouraging or tried to overturn the women's birth plan or pregnancy behaviours. P10 wanted to deliver with no epidural.

> *P10 – "Although it was painful at the time, after she was delivered, it felt quite amazing, and there wasn't any sort of drowsiness or anything, so I was able to go see her as soon as I could, whereas if I had an epidural I would've been waiting until that wore off, so it was quite, yeah, so I dunno, I'm pretty stubborn as well so they were like 'You sure you don't want any pain relief?' and, 'no no no no no, I'm good!'"*

It is unfortunate that P10 had to employ her stubbornness when convincing the hospital staff that she did not want to have an epidural. Further, there were mothers who were nearly persuaded by family members to drink during the pregnancy.

> *P3 – "I didn't drink, but I had to deal with a lot of people going 'Oh one glass won't hurt' and I was like 'no, not going there, not going there'… My mom, her big argument was that, 'well the French drink through their pregnancies and they're fine'."*

P3's experience was not unique, as 2 others also experienced external pressure to drink while pregnant, showing the variety of pressures on pregnant women to act a certain way.

4.8 Summary

The findings represent a thematic analysis of 6 identified topics that span across the data. Firstly, prenatal preparedness was identified as a recurrent theme, where women commented on their mostly negative feelings towards prenatal class content and barriers to access, as well as experiences with birth and pregnancy preparatory knowledge gained from their PCP. Next, working while pregnant was a common theme, which posed for some, access issues with getting to appointments (medical or social), as well as seclusion from the exhaustion and lack of social benefits. Few others documented feeling somewhat supported by their work environment in some way, like having considerate management or resourceful friends at their place of employment. Further, birth expectations were

identified as frequently different than expected - as might be assumed in a preterm birth population. As well, women recounted that medical interventions and birth plans that were not achieved. Place and space as an influence on access was a more wide-spanning theme because it addresses the overall barriers women did or didn't experience to various services or resources with regard to location and time/schedules. A noticeable spatial variation in prenatal care classes and postnatal care services was observed between the cities of Hamilton and Burlington, where Burlington had much less resources than Hamilton in general, but both were generally lacking prenatal resources of any kind. Supports and resources attainment was a large theme as well because it impacts many topics. The main reflections on social support were that it was sought out for a variety of reasons and on a variety of platforms. Word of mouth social interactions seemed to increase women's access to various services and resources, while women frequently utilized online resources like support groups or Facebook groups to find relevant health or social connections. Lastly, it was found that there were recurrences of similar attitudes in decision-making while pregnant and knowledge expectations. Some women wanted to know a lot about their pregnancy, and take charge of healthy action, but there were more women who entrusted their PCP with that duty and/or didn't recognize the expected knowledge or responsibility of a pregnant women in the light of medical providers.

5. Discussion

5.1 Summary

This chapter will provide a summary of the results, and interpretations of the results situated in the literature, followed by an explanation for information channels and structural change. Future research and recommendations will be made throughout, and lastly, limitations of the study will be outlined.

Recall the objectives of this study were to gain a deeper understanding of the experiences and perceptions of mothers whose first pregnancy was a preterm baby, and to learn about access concerns of mothers throughout their pregnancies.

There were six themes identified in the data: *1) prenatal preparedness; 2) working while pregnant; 3) delivery expectations; 4) place and space; 5) supports and resource attainment; and 6) attitudes and knowledge*. Not all themes relate to all objectives, but together they form a narrative that highlights both individual and community level characteristics that influenced mother's perceptions and overall experiences during their preterm pregnancy.

Multiple perceptions about health care, resource use, and pregnancy experiences were compiled primarily through interviews with thirteen women and two key informants, and further understood by some general observations of post-natal program use. Although

there were many perceptions and experiences discussed, overall there were prominent patterns throughout the data.

Of all the women interviewed, there was an average of 4 self-identified risk factors for preterm birth – meaning that they either checked off risk factors from a list that was given to them, or they talked about a risk factor in their interview. All the women were on their first pregnancy and resided in Hamilton or Burlington, Ontario. All women were Caucasian except for one woman who identified as Native-British.

Some main discoveries were that most of the women had very physical- and time-demanding jobs and often referred to them as stressful. Additionally, women were most able to access resources to be more knowledgeable of their own health needs when they had friends, coworkers, or family that were pregnant at the same time. Sharing a similar experience promoted sharing of information and the opportunity to support each other throughout pregnancy. There was also a large presence of online support throughout pregnancy that came out of this data. Lastly, there were inconsistencies between the perceptions of typical expected care and expected needs, and in general caring for oneself. In talking to mothers and key informants, it was clear that the women experienced confusion on whether there were any up-to-date and accurate educational and preparatory resources available for prenatal women. Completing a few web searches corroborated the inferences made by the participants that there is a lack of clarity on prenatal classes and prenatal expectations.

In keeping with Penchansky & Thomas' (1981) access dimensions, it is evident that women's health practices and use of health services were affected by aspects of availability, accessibility, acceptability, affordability, and accommodation. Overall, women's perceptions of their pregnancies were definitely influenced by their surroundings, by their prior knowledge and resources, by their support system, and by the health care service they received. Additionally, there are two overarching topics that permeate through all of these themes, which are 1) knowledge and information flow, and 2) a need for structural change.

5.2 Prenatal Preparedness

Similar to women's knowledge influencing their decision-making and informed care, women with more information were generally more prepared for pregnancy and preterm labour. Having knowledge meant that women would specifically be more prepared about the challenges, interventions, and expectations of pregnancy, birth, and postpartum. The source of this knowledge was primarily women's prenatal care, which included advice and recommendations from PCPs and the attendance of [educational] prenatal classes.

Women feel more prepared for their labour if they have information given to them throughout their pregnancies (Gibbins & Thomson, 2001). Benefits of pregnancy and birth preparation are: less fear of labour pain, feeling in control during the experience (Melender, 2002; Gibbins & Thomson, 2001), feeling confident to make own decisions

(Harrison et al., 2003), and improvement of birth outcomes (Feldman et al., 2000). The majority of women in this study seemed to have less information than they effectively could have had, and their feelings and experiences are consistent with the literature; women did fear labour pain and complications, they often let their care providers make unexplained decisions on their behalf, and they all had a poor birth outcome.

Women want to be prepared to become a mother, not just prepared for *having a baby* (Barclay et al., 1997). In fact, seeing other babies or other parents often enables women to feel better prepared in becoming a mother themselves (Barclay et al., 1997). The results of this study are similar to Barclay et al. (1997) in the sense that women reported feeling more prepared to be pregnant/have a baby themselves just by having other mothers around or by having experiences with children or babies in their families and jobs. The difference is that somehow the event of being *around* babies or children made women in this study more confident for *being* pregnant and *having* a baby. This could be seen as a facilitator in confidence, decision-making, and knowledge. However, if the appropriate knowledge is not transferred to these women through their experiences of being around babies, then they can develop a false sense of confidence where they think they are prepared for pregnancy/motherhood but in fact are not.

While not mandatory, prenatal classes are supposed to be informative, stress-relieving, and overall a provision of strategies and competencies for pregnancy and the early birth stages (BSRC, 2006). Prenatal classes are certainly not all the same as a variety of topics

are widely discussed, such as making healthy choices, watching your bodily and emotional changes over time, and ultimately preparing you for birth and labour (BSRC, 2006; City of Hamilton, 2016).

In this study, women frequently assumed that prenatal classes were only for the birthing component of their pregnancy, which was evident because most women who did or were planning to attend classes scheduled them for the last month of their pregnancy. There are many childbirth-specific classes, so perhaps mothers were only seeking these and did not know they had a variety of options available to them. Regardless, those who did attend classes largely concluded that they were not realistic or not helpful. This may be explained by some literature suggesting that attendance of prenatal classes is not positively associated with better birth outcomes (e.g. Kogan et al., 1994; Sturrock & Johnson, 1990). However, more recent research concludes that certain arrangements of prenatal care can surely have an impact (even if indirectly) on birth outcomes (Benediktsson et al., 2013; Ickovicks et al., 2007). Quality of the prenatal education as well as the actual service delivery in a given area may be poorly planned, leading to negative perceptions or a lack of uptake in the first place (Benediktsson et al., 2013; Tough et al., 2007). In the current study, prenatal classes were also reportedly expensive and had unfavourable schedules, but mostly the content was noticeably inadequate.

5.3 Working While Pregnant

Women in this study held full-time employment while being pregnant. Work was exhausting for most of the women, and was a barrier to free time. Work did influence the level of access to health care and social needs. For some women, work contributed to them feeling ostracized or lonely, while to other women, work facilitated access to supportive people.

Working in an unsupportive environment (Glazier et al., 2004), and working in a standing position for more than 3-6 hours a day (Mozurkewich et al., 2000; Saurel-Cubizolles et al., 2004) has been shown to negatively affect birth outcomes. The women in this study were frequently standing and about half of them felt supported by places and people from outside of their workplaces. Being a working pregnant woman does not necessarily lead to poor maternal outcomes (Berkowitz & Papiernik, 1993), but it does present indirect barriers to accessing care via circumstances like taking time off work without pay (Wellstood et al., 2006). Moreover, work-related psychosocial stress has been shown to negatively affect birth outcomes (Lee et al., 2011). Women in this study did comment on the stress of their workplaces (commute, hours, work itself) and how tired they were when working. Additionally, the majority of women in this study had middle-class to high-class jobs. Furthermore, women spent a lot of their time at work, so for those who felt lonely in their workplace and potentially less supported, this seemed to be a play a larger role in their exhaustion and in their work-stress. For those that did feel supported by their workplaces, it was largely due to the community of women who also worked

there and the experiences that they shared among each other. Noteworthy though are the few bosses who were mentioned as supportive throughout the experience and made it easier for women to take breaks, feel safer, and to attend appointments when needed.

5.4 Delivery Expectations

There were many interventions during women's childbirths from this study. Hospital interventions cost the health care system, they contribute to uncomfortable birth experiences, and they are sometimes unnecessary. Additionally, multiple women identified that their birthing process did not go according to plan. When a woman does not have a birth/delivery go according to plan, it can be a traumatic experience (Beck, 2004). Seeing as the study population is all premature birth mothers, it is highly likely that none of these births went to plan.

Birth plans aid in reduced fear and pain during childbirth (Lundgren et al., 2003), although birth plans do not have any direct impact on neonatal outcomes (Hidalgo-Lopezosa et al., 2013). One study with an admittedly lack of data has shown birth plans to increase the amount of perineal tears and increase C-sections (Hadar et al., 2013). Women in the current study were unhappy or fearful when their expectations for birth were not met, so although a birth plan gone awry is not a causal factor in having a preterm birth, the perspective may have put women in a mindset of not trusting their PCP, or impacted possible interventions used, like episiotomy, epidural, or C-section. Birth plans do however help in communication with the woman and her PCP, and also, women still

value having the opportunity to have a birth plan (Hidalgo-Lopezosa et al., 2013; Lundgren et al., 2013). Because of this, it is worth further exploring the impacts and benefits of having a birth plan. Particularly, the studies above considered written out survey-like birth plans, but the birth plans discussed in this study were much more verbal, casual, and expectation-based.

The majority of women in this study identified that they had normal pregnancies, a number of who specifically identified that it was only normal up until their birth experience or who explained away bigger pregnancy concerns, in spite of their normal pregnancy. This is unexpected, as the mothers interviewed all had preterm births, which suggests that at the least, some of the mothers likely experienced abnormal pregnancies even before labour. The view that their pregnancies were normal up until they gave birth is unlike the medical definition of a normal pregnancy, which is not restricted to the time of labour, but consists of healthy women who attended their examinations at proper intervals, who had no irregularities such as preeclampsia or hypertension, and who also had a healthy spontaneous vaginal labour (Van Oppen et al., 1996). However, in the literature, the criteria for a 'normal pregnancy' is almost always lacking and/or vague in description, is more inclusive of intervention and medication use, and is more tolerant on birth outcomes outside of 'healthy' (e.g., Conway & Deb, 2005). Normal birth and not normal (or abnormal) births are often seen as a dichotomy, whereas they could be seen as opposite ends of a spectrum, with a variety of outcomes and risks in between.

5.5 Place & Space

Women's explicit surroundings played a role in how they felt and what choices they

made, which ultimately affected their access to resources. Similar to the work section,

pregnant women who worked long hours tended to stay home more as they had less free

time for leisure or educational activities – especially for those who worked further away.

Recall that the women were recruited via OEYCs and as such they were out attending

activities with their infants, which reflects the women's sentiments that it is easier and

more desirable to access resources in the community post-birth.

Although transportation is seen as a barrier to health care access (Syed et al., 2013), in

this study, the majority of women fell within the middle-to-upper class category, and

most of them drove their own vehicle, reducing their overall expected barriers to access.

Women sometimes said they understood that the resources they had were not reflective of

other women and related to the struggle of not having a car, money, and information.

Still, the majority of women were influenced by scheduling, money, and time when

making decisions about their care and activities, consistent with previous research (e.g.

Wellstood et al., 2004; Ickovicks et al., 2007).

The trends in access to prenatal care and affiliated activities could be explained by

Phillippi & Roman's (2013) Motivation-Facilitation Theory, which postulates that women

need to be motivated to begin care, and further that the care should be in a conducive

environment. The lack of service utilization pre-birth among the mothers could also be because of the location and lack of services offered prenatally.

5.6 Supports and Resource Attainment

Consistently, mothers accessed the Internet during their pregnancies for both peer support and information gain. Particularly, Facebook was a common internet resource, among many other types of sites.

Internet usage related to health related queries does occur predominantly among women of higher socioeconomic status (Hesse, 2005), which is true of this study's population. Development and childbirth information are common internet searches throughout pregnancy (Larsson, 2009), but more recently, the Internet is being used for networking and peer support, in addition to information gain (Lagan et al., 2010; Lasker et al., 2005). The women in this study did sometimes use the Internet to find health answers and general information, but they more frequently and primarily used online resources as a way to connect with women at the same stage in their pregnancy, to make friends, to appease fears, and to generally explore pregnancy.

Given the difficulty of locating women who had preterm births (without accessing hospital records), and given the approximate rate of preterm birth in Ontario (~8.0%), it appears that this population of women is not easily accessed in general. Considering support benefits/needs of this population, it seems easier and more likely for women to

gain support via online platforms than by any other route. Similar to premature birth mothers, Lasker et al. (2005) suggest that people with illness can better and more likely find unique resources to their health issues online because these may not be as easily located in the community. To this end, various Facebook groups among mothers in this study actually served this exact purpose. Schedule and money considerations to access (previously discussed) in addition to proximity and specificity considerations, are all motivations to accessing Facebook or similar online platforms. These findings strengthen the understanding of Thoren et al. (2013) who found that parents of preterm babies used Facebook groups for support and information, but also called for more research in understanding online platform usage in the premature parent population.

Additionally, the search purposes and the diversity of online resources within this relatively small (n=13) group of women, illustrates the demand for more curated community resources. The strength in online resources is demonstrated through, but not limited to: women feeling less isolated during pregnancy (Lowe et al., 2009) and women feeling more confident to make decisions during pregnancy (Lagan et al., 2010).

Word of mouth was also found to be a contributor to gaining access to resources and information. Similar to mothers sharing like-experiences with women on online platforms to feel less isolated, mothers frequently found support and learned of resources through women who have been pregnant before. Women who did not gain information through word of mouth were less likely to feel supported during pregnancy. Word of mouth is a

powerful tool in impacting people's behaviours and attitudes, and is increasingly being used in marketing campaigns due to its efficacy (Lang & Lawson, 2013); so it is not surprising the amount that women benefited from this type of communication. This may be an indication of the necessity of an established social infrastructure for women to access and connect with others alike.

5.7 Attitudes and Knowledge

Women typically formed a relationship with their primary care provider centered on receiving advice and taking instructions. Women often had somewhat negative feelings towards their birth after-the-fact, but leading up to the birth were passive and hopeful. It was noticed that perhaps making decisions and feeling confident in the outcome of childbirth had something to do with the knowledge that women had, or the type of relationship between her and her PCP.

Decision-making is a channel in which we see this theme emerge. Decision-making in pregnancy is tethered to one's trust in their health care provider, where trust allows women to take a more passive role in pregnancy and birth decisions (Harrison et al., 2003). Trust also allows women to feel more agreeable to the advice given by their PCP (Mainous et al., 2001). Women in this study often sought advice from their PCP, so it is possible that patient-PCP trust allowed for antenatal passive decisiveness.

Women have previously reported not wanting to be involved in decision-making during labour (Moffat, 2007), but women have also reported wanting to be involved for high-risk pregnancy decisions (Harrison et al., 2003). Being able to make decisions or wanting to make decisions can come from having information and knowledge. The findings demonstrate that women infrequently had enough knowledge about the birth experience to make confident, informed decisions about what they did or did not want, or what was an actual choice versus what was medically necessary during labour. Women rarely wanted to be involved in labour decisions, but when they did, they were confident, like the woman who was not going to have an epidural even though her care providers were pushing for it. However, women expressed their interest in making more decisions throughout their pregnancy.

Having informed choice means that women can make evidence-based decisions; it means that women have access to maternal education that includes content on the risks, benefits, and alternatives of pregnancy and childbirth (Panel OMCE, 2006). Women want to be treated on an individual level in their health care setting through an information-rich relationship with their health care providers to help make informed decisions (Handler et al., 1996). For instance, mothers have been shown to have incorrect understandings or no knowledge on complications regardless of if they experienced them or not (Declercq et al., 2007).

Not only is knowledge on complications and interventions lacking, but general pregnancy knowledge and confidence in one's health status and decisions is being challenged. Advice or recommendations given to women from various sources, but in this study particularly from other mothers (e.g., regarding drinking) may be a contributor to women having mixed feelings about what their role in maternal health care is. Perhaps, if both PCP and women's attitudes toward maternal knowledge and health care involvement were aligned with one another, mothers may have been better aware and increasingly informed about interventions and normal delivery expectations – whatever that may be. Although it is not unexpected, the media normalizes births that are highly medicalized and contain with interventions (Morris & McInerney, 2010). These representations and stories of pregnancies and birth may affect women's perceptions of antenatal health care and their subsequent role therein.

These findings contribute to our knowledge on the quality of (maternal) care where the ability to make informed decisions comes from having access to quality health information in the first place, and secondly, being in an atmosphere that encourages maternal-centric care, essentially changing the culture and increasing acceptability of maternal involvement.

5.8 Contributions to Theory

5.8.1 Access

Recall the concept of access and the affiliated components: availability, accessibility, accommodation, affordability, and acceptability. Each noted dimension contributes to issues of access in terms of utilization and satisfaction of health care services (Penchansky & Thomas, 1981). These dimensions all contribute to measuring access to health care resources and services in a given population and within a given area.

Availability refers to the supply of resources and services in terms of volume and need. It was noticed that the prenatal classes that mothers wanted to participate in were in abundance in Hamilton, but not so much in Burlington. However, mothers recounted trouble *accessing* these services – not explicitly because of location, but more so because of *accommodations* and *affordability* of the services. Scheduling and time constraints of both a woman's personal work hours and the hours outlined by various prenatal education services, in addition to having to pay for educational prenatal classes, proved to be a barrier to access. *Acceptability* refers to the attitudes between clients and care providers. In this study, women's knowledge exchanges and confidence in decision-making, showed a lack of acceptability.

The pattern of Burlington mothers using Hamilton resources suggests a reevaluation of locations or of service structure. However, the noted benefits of having universal

accommodation considerations (e.g., drop-in, first come-first serve) currently outweigh geographic boundaries for services like OEYCs and prenatal classes.

Women having considerably more access to support and not explicitly to health care services can also be explained via the access dimensions above. *Accessibility* was a non-issue in this sample because women had access to the Internet (at home) and frequently cited using Google, Facebook, or similar platforms for information gain. The online resources for women were saturated and therefore seemingly *available* for my sample. It was something that is easily *accommodated* for because of considerations like the ease of operation of internet browsing and the lack of judgement from one's own home. *Affordability* was also a non-issue in seeking internet-supportive resources, and actually works as a motivator to access in this case. Reaching out for support was arguably *acceptable* because women frequently found something they related to on the Internet: an app for their pregnancy progress, an illness-specific support group, a multiple pregnancy group, etc. Overall, having better access to supportive online resources educates women and prepares them better for future concerns.

5.8.2 Health Belief Model

This study specifically looks at women's perceptions and experiences with various pregnancy and birth scenarios and addressed how these influence some pregnancy behaviours. Rosenstock's (1974) Health Belief Model proposes that people will make decisions and change behaviours based on their perception of their health problem. The

model also includes a slight cost-benefit analysis on the woman's part in essentially weighing if a change in behaviour will be worth the benefit. Considering that in this study, women for the most part did not perceive themselves as having an abnormal pregnancy, and at times had incorrect health information, explains why the experience of a premature birth was often a surprise. This finding concurs with, and emphasizes the importance of the need to design prenatal care options in such a way that increases women's perceived susceptibility of having a poor birth outcome (to ask as an incentive to start and continue care) (Stout, 1997). Nonetheless, there were some women who attempted to manage behavioural risk factors for preterm birth and labour such as prolonged standing, drinking alcohol, or exercising within medically safe limits. Here, women faced barriers such as peer pressure, job requirements, and unknown recommendations that made it more difficult to oppose their current risk factors. This implies that in addition to just women's perceptions impacting behaviour, there is a considerable portion dedicated to external forces impacting the likelihood of women fully taking action.

Moreover, women in this study attended their prenatal care appointments, so perhaps in this case it is best to ask women specifically what further deters them from attending prenatal classes instead. For instance, it was found that one woman in this study was deterred from attending birthing classes because she was a single mother and felt she might be judged. This has been similarly noticed in other studies (Tough et al., 2007; Sword, 2003), where women felt ostracized to attend prenatal classes alone. This one

example has wide implications in that the HNHB LHIN has a high rate of female lone

parent mothers (~20%) (MNSC, 2007), who may just feel the same way and who may be

influenced by their own perceptions of services. Further, women who experience feelings

of self-consciousness or isolation due to race or income for example, may have these

same barriers.

5.9 Contributions to Policy & Practice

A concept noticed across all themes is the need for operational/structural change

concerning access issues for women experiencing pregnancy. This applies to the areas of

knowledge acquisition, employment, service delivery, and health care client and provider

expectations. To make effective change, revised or additional policies and practices could

be implemented.

5.9.1 Knowledge Acquisition

It was earlier identified that it is beneficial for women to be prepared for their pregnancies

and births. However, women having incorrect information or a false confidence in their

current knowledge may prevent women from seeking additional resources. Having some

control over knowledge acquisition for women of childbearing age could better prepare

women or encourage women to further educate themselves. Although, there is a clear

need to separate women's negative perceptions of prenatal educational classes from

actually uninformative classes. As women in this study mostly only attended childbirth-

specific prenatal classes, they might not know the utility of attending the classes they

chose not to attend and subsequently the information they did not learn. Further research should consider the utility and the proportions of pregnancy related prenatal classes to birthing prenatal classes. Since LHINs in Ontario are a large contributor to health care planning and funding, it may be beneficial to look at other models of prenatal care and educational prenatal class programming to see discrepancies in uptake and perceptions. For instance, European countries frequently show better uptake of prenatal care (Beeckman et al., 2010) and also lower levels of poor birth outcomes like prematurity and low birth weight (Kin & Saada, 2013). Also, not only can prenatal classes contribute to better birth outcomes, but also they inherently serve as a tailored support group, because these women will typically live in the same geographic region and be in the same stage of pregnancy.

Another knowledge concern is with women utilizing the Internet for increasing access to health care knowledge. Women are not frequently disclosing what they are learning and searching on the Internet to their PCP (Larsson, 2009). However, the benefits of online information acquisition can be seen via instantaneous access to information, anonymity for users if they choose, and overall less costs in resources (Plantin & Daneback, 2009). Growing a correct and tailored online resource for this study population would increase credibility of information being retrieved by women, but may also, like most online 'symptom-checker' type platforms be taken out of context. Seeing as Facebook was a large source of online and other knowledge acquisition, perhaps this is a good place to focus promotion and education resources within the HNHB LHIN. Additionally, as the

HNHB LHIN is tied for second highest rate (below Toronto) of preterm births in Ontario (BORN, 2013), using online resources should be a priority when mothers themselves are consistently seeking out information in this way.

Increasing word-of-mouth, the next important platform for knowledge acquisition, may itself not be directly controllable, and is dependent on the size of an individual's social capital. Therefore, to ensure women have access to the resources and social support available online, health care professionals should assume the role of sharing the information and directing women to appropriate social-support services both throughout their pregnancies and after. Health professionals taking on this role is beneficial for control and regulation purposes. Additionally information shared will be ideally most credible from health care professionals, which may in turn reduce the need to verify information.

5.9.2 Employment

Attention to pregnant women's work-life as it relates to time management and space (distances) may help to further understand work-incurred barriers to health care access. This study describes what women choose to do with their time outside of (often lengthy) work hours, and highlights a factor of distance as well as time impacting behaviour choices and resource access. A suggested change to women's work expectations during pregnancy is to increase break time and provide extra leave days for prenatal appointments. Currently, women are expected to use their vacation or sick days for this

purpose, which often do not cover pregnancy required appointment times, even if the party has not used any vacation or sick days. The major benefit to an implementation of this sort is a serious reduction in women's stress, increased mental and physical well-being, and subsequently, the promotion of better birth outcomes. Not only might there be less premature births in regions where women are given more time to prepare medically and mentally through their employers, but poor maternal health outcomes might be avoided as well. Understandably, this implementation would incur lost work hours for employers, and the relatively short-term lost productivity would be costly, but the cost-benefit analysis comparing that to poor birth or maternal outcomes may be worth it in the end – especially if there are government/provincial incentives to provide better pregnancy benefits.

It is worth noting that the Ontario Human Rights Commission (2016) states that women have a right to altered work duties for the mother's health benefits, however, the vagueness is left to interpretation. As bosses are not typically held accountable to accommodating women's pregnancy needs, perhaps more specific guidelines are necessary if in no other place, at least in redefining women's employment rights as pregnant women.

5.9.3 Client-Provider Expectations

Pregnant women were often seen to have preemptive expectations of pregnancy and birth experiences, where some were helpful to her, and some were not. The term 'normal

pregnancy' is of particular interest and deserves further scrutiny. It would be beneficial to explore both health care provider and women's thoughts on what constitutes both a 'normal' pregnancy and a 'normal' birth, and to also explore how perceptions of normalcy in pregnancy and birth affect women and care settings. Implementing a working, practical definition that both health care providers as well as clients use will increase clarity and facilitate more narrow expectations for birth and pregnancy, instead of what women identified in this study of either normal, or completely not normal.

PCMCH (2016) concludes that pregnant women need autonomy and informed choice, and that women need more information in order to make health care decisions, where various levels of maternal care need to be explained better to help that cause. For instance, having aligned client-provider expectations about side effects and complications from interventions in childbirth may help women to understand outcomes better and make more informed decisions leading up to their birth. The women in this study had many interventions that perhaps could have been reduced had they been better informed. An individualized and context-specific approach to health care is recognized as a desirable direction for pregnancy and birth care altogether (Cooke et al., 2010), so implementing this style of maternal and infant care in this region could have many positive impacts to women and their newborns.

5.9.4 Service Delivery

The MNSC (2007) reports that there is a decline in maternity health professionals within the HNHB LHIN, and that there is a lack of coordination among maternity services. In particular, prenatal care coordination among health care workers is not well documented, and is undefined, leaving behind inconsistencies and gaps in what is being done by health care workers (MNSC, 2007). Women in this study affirmed the gaps present in prenatal class content and organization, and key informants affirmed the gaps in prenatal supports in both Hamilton and Burlington. The variation and distribution of prenatal class offerings within Hamilton and Burlington (illustrated by Figure 5) in addition to the OEYC location utilization patterns seen in the findings reflect these conclusions as well. This offset of social services could be a result of the income disparity among the two locations: where Hamilton has the largest amount of low income residents in the HNHB LHIN, and Burlington has the lowest. Further research should be conducted in regions with similar income and service patterns to confirm if this service distribution pattern is a function of community-level income disparities. Additionally, it would be useful to study women's perceptions of prenatal education classes and various social services both pre- and post-birth in both Hamilton and Burlington to explore how women's feelings differ across the locations. Doing so may help challenge the reasoning for locating services and distributing resources within the LHIN. It seems possible that prenatal care and prenatal classes on the whole are due for a rebranding. Given the opinions on the outdated classes, and how many women felt already prepared with non-relevant experiences, perhaps

women's health services needs to refocus on what prenatal care is and why it is necessary, *in addition* to correcting old materials and increasing promotion.

Perceptions about and experiences with various pregnancy concerns like prenatal vitamins and healthy work recommendations emphasized concerns about the variable expectations and advice given to different women, depending on who their PCP was and what questions they asked. There seemed to be a pattern of women feeling more confident or ready because they did more research, had more friends, or generally asked more questions. However, this assumption cannot be made of all women, and services should be delivered with both basic and universal recommendations for healthy behaviour. More than once, women in this study had to reach outside of their PCP to learn about something prenatal care appointments should have covered. Given this, an evaluation of current prenatal care practices should be undertaken in these regions, and further studies should be wary of information flow through maternal health services. Additionally, this issue precludes the possible disconnect between how women think they should prepare for pregnancy, and how PCPs think women should prepare for pregnancy.

5.10 Limitations

The most pertinent limitation in this study was concerned with sampling and recruitment. My sampling method assumed that the same women who intimately utilized NICU or Public Health care services were recommended to use (key informants and public health confirmed this) and subsequently were using their community OEYC. This assumption

was disadvantageous for accessing women who were working instead of child minding, who did not realize about or care for using OEYC services in the first place, or who had premature babies who required extra attention elsewhere so were far less accessible. Additionally, of the sample obtained, the women primarily were representative of the middle-to-upper class category. As socioeconomic status plays a large role in lifestyles and in health, it would have been more wide reaching had the sample included more lower-to-middle income women – especially given the diversity of demographic over the HNHB LHIN.

Another limitation was that there were no health care workers in my sample. This made it difficult to confirm or deny, elaborate on, or clarify comments that women made during interviews. For example, the aversion of women accessing prenatal classes was explained to an extent (not interested, poor content, cost), but it remains unclear the level the PCP's involvement. This opens the question, 'what is the structure of maternal education promotion over the duration of pregnancy?' However, this study is meant to focus on descriptions of women's perceptions and experiences, which was achieved, so this is supplementary. Also, all of the women in the sample attended most or all of their prenatal care appointments, suggesting there is a lack of documented perspective from women who probably faced many other barriers that were not identified by the women here.

Also, this study spans a 9-month time frame and is essentially a snapshot into what has already happened. This implies recall bias on the part of the mother, which may alter the events that they recalled and may also influence their feelings towards those events. Further research could complete similar analyses over the course of pregnancy so that 1) immediate feelings and experiences are documented, and 2) so that multi-level evaluations could be made. For example, following a group of women who are all participating in prenatal classes allows for future comparative analyses on those who had an adverse birth outcome versus those who did not.

6. Conclusions

The following themes identified in the data were prenatal preparedness, working while pregnant, delivery expectations, place and space, supports and resources attainment, and attitudes and knowledge. The themes highlight topics and similarities among women's perceptions and experiences of being pregnant. Together, these themes touch on access considerations from structural access, to operational access, to social and temporal access. A recurrent pattern in the data is the idea of information flow and knowledge gain, and their importance as facilitators to access. Also evident, is the importance of support for women throughout pregnancy, both personally and structurally.

The concept of access seen in this analysis was conceptualized via Penchansky & Thomas' (1981) five dimensions: availability, accessibility, accommodation, affordability, and acceptability. Access to prenatal care, which is inclusive of prenatal classes and positively supportive resources, is affected by each of the dimensions listed

above (and described in Table 1). Also, the interpretations are consistent with Rosenstock's (1974) Health Belief Model, where the likelihood of taking an action depends on considerations like the person's perceived threat to a poor outcome, and their perceived benefits of taking a preventive action.

In concluding the findings and interpretations of this study, it is recommended that further research and considerations are made in the following areas. First, understanding about women's knowledge acquisition preferences can help in adherence to recommendations and learning over the course of pregnancy. Second, the inclusion of employers as advocates for women's health can affect women's access to prenatal health care resources. Third, service delivery structures are constantly changing, but so are women's roles in society. Delivery structures for prenatal classes and medical resources should aim to accommodate better the needs of pregnant women, and look to their perspectives as markers on if the structures in place are beneficial to them. Last, health care client and provider expectations need to be aligned, so further research is recommended to enhance our understanding of where pregnancy knowledge and learning responsibilities lie. Essentially, a call to rebrand pregnancy into a more representative, and more mother-involved experience is suggested.

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Appendix A: Ethics Certificate

	McMaster University Research Ethics Board (MREB)
McMaster University — Inspiring Innovation and Discovery	c/o Research Office for Administrative Development and Support, MREB Secretariat, GH-305, e-mail: ethicsoffice@mcmaster.ca
	CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH

Application Status: New ☐ **Addendum** ☑ **Project Number:** 2014 144

TITLE OF RESEARCH PROJECT:

    Perceptions of women regarding their pregnancy, neighborhood, and preterm birth experience.

Faculty Investigator(s)/ Supervisor(s)	Dept./Address	Phone	E-Mail
J. Eyles	Geography	905-525-91	eyles@mcmaster.ca
Student Investigator(s)	**Dept./Address**	**Phone**	**E-Mail**
N. Urbalonis	Geography	905-525914	urbalon@mcmaster.ca

The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB:

☐ The application protocol is cleared as presented without questions or requests for modification.

☑ The application protocol is cleared as revised without questions or requests for modification.

☐ The application protocol is cleared subject to clarification and/or modification as appended or identified below:

COMMENTS AND CONDITIONS: Ongoing clearance is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and cleared before any alterations are made to the research.

Amendment#2, cleared June 30, 2015

Reporting Frequency:	**Annual:** Aug-27-2016	**Other:**

Date: Aug-27-2014 **Vice Chair, C. Anderson:**

Appendix B: Letter of Information/Consent

DATE: _____

Appendix 7
LETTER OF INFORMATION / CONSENT

A Study of/about Perceptions of women regarding their pregnancy, neighborhood, and preterm birth experience

Investigators: Nicole Urbalonis

Faculty Supervisor:
Dr. John Eyles
Department of Geography
McMaster University
Hamilton, Ontario, Canada
McMaster University

(905) 525-9140 ext. 23152
E-mail: eyles@mcmaster.ca

Student Investigator:
Nicole Urbalonis
Department of Geography
McMaster University
Hamilton, Ontario, Canada
McMaster University

(905) 525-9140 ext. 20440
E-mail: urbalon@mcmaster.ca

Purpose of the Study / *What am I (are we) trying to discover?*
I am doing this research study for the completion of my Master of Arts thesis in the School of Geography and Earth Sciences. The purpose of this research is to describe the experiences of women who have given birth preterm in the regions of Hamilton, Niagara, Haldimand, and Brant. I will look more closely at how women perceive the influences of biological and other types of factors in relation to their pregnancies, deliveries, and more specifically in the outcome of a preterm birth. I am hoping to learn if there are atypical factors that are associated with preterm birth in either region, how women perceive preterm birth contributors, and identify and describe any differences or patterns among the noted regions.

Procedures involved in the Research / What will happen during the study?
I am going to conduct an approximately 30 minute interview where there will be a series of fairly open-ended questions. The questions will be about your workplace, the population that access programs, and your opinions. Here is an example of a question that may be asked: *Tell me about the programs here at the OEYC?* I will audio record the interview with your permission for accuracy and transcribe it at a later date. Once I have preliminary findings, I will send you a brief copy of them and ask that you read them over for trustworthiness. At this point, I will complete my data analysis and write up and I will then send you a copy of my overall findings.

Potential Harms, Risks or Discomforts / Are there any risks to doing this study?
The risks involved in participating in this study are minimal. You may feel uncomfortable or embarrassed in answering questions. Please note that you do not need to answer anything you do not want to and you can withdraw from the study at any time. I describe below the measures that I am taking to protect your privacy.

Potential Benefits / Are there any benefits to doing this study?

   The research will not benefit you directly. I hope to learn more about women's pregnancy and birth experiences with relation to their circumstances and their respective geographic regions. I hope that what is learned as a result of this study will help us to better understand preterm birth and the relationship to various factors. If and when published, this will contribute to the scientific community and potentially to your community.

Confidentiality / Who will know what I said or did in the study?

   You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one but me will know whether you participated unless you choose to tell them. In addition, I will use pseudonyms in the report. However, we are often identifiable through the stories we tell so please keep this in mind in deciding what to tell me. Your privacy and confidentiality will be protected by the measures listed below:

   -Password protected computer
   -Locked office
   -Encrypted file transfers
   -No personal identifiers used (i.e. names)
   -Password protected internet connection
   -Correspondence from McMaster email account
   -Delete all data after study is completed (approximately June 2015)

b) Legally Required Disclosure

   Although I will protect your privacy as outlined above, if the law requires it, I will have to reveal certain personal information (e.g., child abuse).

Participation and Withdrawal / What if I change my mind about being in the study?

   Your participation in this study is voluntary, it is your choice to be part of the study or not. If you decide to be part of the study, you can stop (withdraw), from the interview for whatever reason, even after signing the consent form or partway through the study or up until approximately May 1, 2016 (when I expect to be completing my thesis). If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

Information about the Study Results / How do I find out what was learned in this study?

   I expect to have this study completed by approximately May 2016. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact me at:
Email: urbalon@mcmaster.ca, work phone: (905) 525 9140 x 20440, cell: (289)-400-8595.

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.
If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

    McMaster Research Ethics Secretariat
    Telephone: (905) 525-9140 ext. 23142
    c/o Research Office for Administrative Development and Support
    E-mail: ethicsoffice@mcmaster.ca

CONSENT

- I have read the information presented in the information letter about a study being conducted by Nicole Urbalonis 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 participate in this study, I may withdraw from the study at any time or up until approximately May 1st, 2016
- I have been given a copy of this form.
- I agree to participate in the study.

1.
☐ Yes, I agree that the interview can be audio recorded.
☐ No, I do not agree that the interview can be audio recorded.

2.
☐ Yes, I would like to receive a summary of the study's results.
   Please send them to this email address _____
   Or to this mailing address: _____
                                      _____
                                      _____

☐ No, I do not want to receive a summary of the study's results.

3.
I agree to be contacted about a follow-up on the collected data, and understand that I can always decline the request.
☐ Yes. Please contact me at: _____
☐ No.

Signature: _____
Name of Participant (Printed) _____

Appendix C: Recruitment Poster

McMaster University

PARTICIPANTS NEEDED FOR RESEARCH IN MATERNAL EXPERIENCE STUDY

We are looking for women to take part in a study of maternal experience and perceptions in relation to preterm birth.

Women who fit these criteria are asked to participate:

- over 18 years of age
- have given birth <u>preterm</u> within at most 6 years
- resides in Hamilton, Niagara, Haldimand, Norfolk, Burlington, Brant
- speak English
- have not suffered a stillbirth

You will be asked to participate in an interview and will receive a follow up email of the findings and a **$20 grocery store gift card.**

Your participation would involve 1 session, and will be about 30 minutes long.

For more information about this study, or to volunteer for this study, please contact:

Nicole Urbalonis
School of Geography and Earth Sciences
work: 905-525-9140 Ext. 20440 or cell: 289-400-8595
Email: *urbalon@mcmaster.ca*
If you have any concerns of this study or your involvement, please contact
John Eyles (supervisor)
work: 905-525-9140 Ext. 23152
Email: *eyles@mcmaster.ca*

This study has been reviewed by, and received clearance by the McMaster Research Ethics Board.

Call Nicole Urbalonis 289-400-8595 or Email: urbalon@mcmaster.ca

Call Nicole Urbalonis 289-400-8595 or Email: urbalon@mcmaster.ca

Call Nicole Urbalonis 289-400-8595 or Email: urbalon@mcmaster.ca

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Call Nicole Urbalonis 289-400-8595 or Email: urbalon@mcmaster.ca

Call Nicole Urbalonis 289-400-8595 or Email: urbalon@mcmaster.ca

Appendix D: Interview Guide

Appendix 10

Interview Guide

Nicole Urbalonis
Masters Candidate in Geography and Health
Study Title: Perceptions of women regarding their pregnancy, neighborhood, and preterm birth experience

Okay so before we begin I would like to just briefly remind you that this study is about the perceptions women have about maternal experiences, and particularly the influences of preterm birth as a maternal health outcome. Anything that you contribute is valuable. I will not discriminate or judge, and I hope that you feel comfortable conversing freely.

Interviews will be one-on-one and will be open-ended (not just "yes or no" answers). Because of this, the exact wording may change a little from woman to woman. Sometimes I will use other short questions to make sure I understand what you told me or if I need more information when we are talking such as: "So, you are saying that ...?), to get more information ("Please tell me more?") or to learn what you think or feel about something. During the interview, please let me know if you would like to skip a question or if you need to check the meaning of a question. With that said, I am going to begin the interview. Do you have any questions for me?

These first few questions will be about getting to know your recent pregnancy experience a little bit.

Break the ice – *Is this your first child? Is it a boy or a girl? What is his/her name? How long ago did you have him/her? Do you have any other kids?*

1. What were your reactions to finding out that you were expecting? [probe: planned or not?]
2. Did you have any health concerns during your pregnancy? If so, what were the primary concerns? [probe: blood pressure, weight etc.]
3. Do you feel that you experienced a normal pregnancy?
4. Tell me about your labour:
    a. Was it difficult for you or the baby?
    b. Did you or your baby suffer any complications? [probe: how did you respond to it physically, mentally, temporally?]
5. What was your reaction to finding out that you had given birth preterm?
    a. Did you wonder what caused it? Why/why not?
    b. What did your doctor say about it?

Okay, great so far, I would like to ask you a few more questions about lifestyle. Just remember that you do not have to answer all questions if you do not feel like it.

1. What helped you maintain a healthy lifestyle during this pregnancy?
2. Please tell me specifically about any barriers to a healthy diet (and an exercise routine)? [probe: were you recommended a diet, was that diet monitored, did your diet change?]
    a. What were your experiences/expectations concerning consuming enough vitamin-rich food or having enough food in general?
3. Who did you seek advice from during your pregnancy? [probe, did you use it, was it good advice?]
4. Where is the first place you look to/go to when searching for the following:
    1. Health questions about your pregnancy/child
    2. Fun activities
    3. Finding friends/support people
    4. Finding childcare
    5. Places to engage your child
5. Tell me about the prenatal activities that you participated in:
    a. Did you attend prenatal classes [probe: was advice given, was it like a support group]
    b. Did you get together with other soon-to-be moms other than these services? [probe: where, frequency, was it helpful]
    c. Was it easy to find activities catered for your interests/needs in the community
6. Tell me about your attendance of prenatal visits:
    a. Can you remember if you attended all your prenatal appointments?
    b. Were there any challenges to going to them?
7. What was your working environment like?
    a. What were your feelings about the hours, pay, safety, benefits?
8. Can you speak to any stressful events in your life that occurred during your pregnancy, like moving to a new place, fighting with loved ones, financial insecurity, etc?
9. Are you a smoker?
    a. What was your experience with smoking during pregnancy?
10. Do you drink alcohol?
    a. What was your experience with drinking during pregnancy?

The last few questions will be generally about getting to know you and your finances.

1. Are you employed?
2. Are you in a steady partnership?
3. Do you find it easy to get by financially?
4. Do you own or rent your property?

Lastly, is there anything else you would like me to know about your experience?

Great, thank you for all your contributions. I will now ask you to fill out a demographic form.

Appendix E: Demographic Form

Appendix 11

Demographic Form

Nicole Urbalonis
Masters Candidate in Geography and Health
**Study Title: Perceptions of women regarding their pregnancy, neighborhood, and
preterm birth experience**

INSTRUCTIONS: Please fill this in to provide us with some basic background
information about you.
1. My age range is:
   [ ] 18-25,
   [ ] 26-30,
   [ ] 30-35
   [ ] 35-40
   [ ] 40 and up

2. My ethnicity is: _____

3. I'm (Check one):
   [ ] single
   [ ] married
   [ ] separated
   [ ] divorced
   [ ] a common-law spouse
   [ ] prefer not to answer

4. I live in (Check one):
   [ ] Hamilton (Dundas, Ancaster, Waterdown, Hamilton, Stoney Creek, etc.)
   [ ] Burlington
   [ ] Niagara (Grimsby, Welland, St. Catherines, Beamsville, etc.)
   [ ] Brant (Brantford, Burford, Middleport, etc.)
   [ ] Haldimand-Norfolk (Simcoe, Port Dover, Cayuga, Caledonia, Dunnville, etc.)

5. My highest education received is (check all that apply):
   [ ] less than high school

[ ] high school
[ ] certificate/accreditation
[ ] university/college
[ ] graduate program

6. [   ] I have one child.
    [   ] I have more than one child.

7. [ ] I rent my property
    [ ] I own my property

8. Please indicate your total household income:
    ☐ 0 – 23, 999
       24, 000 – 36, 999
       37, 000 – 72, 999
       73, 000 – 100, 000
       > 100, 000
9. I receive social or financial assistance in the capacity of:

_____

_____

   Or, circle here if not applicable: _____N/A_____

Please turn over this brief information sheet and leave it on the table when you leave. Thanks.