

Women's Lived Experience of Risk in Pregnancy

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## Abstract

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Cardiovascular disease (CVD) prevention, treatment and outcomes in women remain largely inequitable globally. Unique sex-specific stages of life, including pregnancy conditions, and their influence on cardiac risk is a growing area of research (Norris et al., 2020). For example, preeclampsia is strongly associated with CVD risk. This connection has led to prevention interventions such as postpartum risk clinics. Research to date on pregnancy and chronic disease is rooted in the medical paradigm of risk and lacks women's lived experience. The present study qualitatively explored illness and risk perceptions of women with risky pregnancy conditions. Some participants felt self-blame for their conditions. Consequences and severity were focused on "baby first", while maternal risk was viewed in the distant future. Aspects of the pregnancy experience, including prompt access to mental health support, was viewed as a "blessing in disguise". Risks, such as lack of agency, and benefits of healthcare risk communication and intervention and implications for practice were also explored.

*Key words:* illness perceptions, pregnancy, cardiovascular disease, phenomenology, health care practice, risk, critical theory

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## Contents

Abstract	ii
Acknowledgements	iii
Table of Contents	iv
List of Tables	vi
Introduction	1
Present Study	10
Method	12
Design	12
Theoretical Orientation	12
Mid-Range Theory	14
Context of Study	16
Sampling and Recruitment	17
Procedure	18
Materials	20
Qualitative Data Analysis	21
Strategies for Vigour	23
Reflexivity	25
Results	27
Participants	27
Theme 1- Lived Experience of Risk	28
Theme 2- Cause and Self-Blame	38
Theme 3- Baby First	47
Theme 4- “Blessing in Disguise”	52
Theme 5- Risk as Inequitably Distributed	57
Theme 6- Medicine’s Role in Risk	64
Discussion	86
Study Advantages and Limitations	109
Conclusion	110
References	112
Appendices	127

## **List of Tables**

Table 1	Advice for Improving Communication about Risk from Participants	85
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## Women's Lived Experience of Risk in Pregnancy

Cardiovascular disease (CVD) remains the number one cause of premature death for women in Canada (GBD Causes of Death Collaborators, 2017). Evidence is growing that women have unique pathophysiologic cardiac mechanisms and effects related to their different stages of life (Norris et al., 2020). One sex-specific life stage and its role in CVD risk that is of growing interest in the literature is pregnancy (Neiger, 2017). Data increasingly links maternal vascular, metabolic, and inflammatory complications of pregnancy with an elevated risk of vascular disease (Nerenberg, Daskalopoulos & Dasgupta, 2014). The conditions that are associated with elevated risk include, but are not limited to, fetal growth restriction, hypertensive disorders of pregnancy, preterm delivery, gestational diabetes (GDM), and HELLP syndrome. The association between pregnancy conditions and future risk is robust. For example, previous preeclampsia increases risk for CVD by more than three-fold (Nerenberg et al., 2014). Furthermore, GDM is not only an independent risk factor for CVD, but also Type 2 Diabetes Mellitus (T2DM). Women with a history of GDM have a 1 in 2 chance of developing T2DM later in life (O'Reilly, 2014). Risk associated with pregnancy conditions is often not in the distant future. For example, nearly 20% of women with GDM in pregnancy will have T2DM within ten years postpartum (Feig, Zinman, Wang & Hux, 2008). Pregnancy has been likened to a cardiovascular "stress-test" and serves as a unique time in a woman's lifespan where future disease risk might be illuminated (Smith, Pudwell & Roddy, 2013). It is well-known that women's cardiac outcomes and treatment continue to be inequitable. For example, after an acute myocardial infarction, women are more likely to die within one year of the event compared to men (Izadnegahdar et al., 2014). Yet, the uptake and practice of unique approaches to clinical care focused on women remain largely absent (Norris, Tannenbaum, Pilote, Wong, Cantor &

McMurtry, 2019). Norris et al. (2020) described the landscape of CVD and women in Canada as the “glaring ‘unders’: under-aware, under-diagnosed and under-treated, under-researched, and under-supported”. Women’s risk profiles are influenced differently than men (Norris et al., 2020). For example, women with diabetes mellitus are two to four times more at risk for heart disease compared with men with DM. Also, the psychological and social experiences of women are different than men. Women are still tasked with unequally more unpaid housework and family responsibilities. As well, women continue to experience discrimination and inequitable pay in the workplace. Gender roles influence health promoting behaviour, including exercise, and stress responses that influence cardiometabolic risk (Lundberg, 2005). These all make the study of behavioural responses in women unique (Norris et al., 2020). Despite the strong data supporting this pregnancy and cardiometabolic disease association, less understanding exists on women’s perceptions of these conditions and how best to support women with these conditions to prevent future CVD. The present study aimed to qualitatively explore women’s illness perceptions and their views on chronic disease risk information from their health care teams with a focus on informing practice.

### **Risk Mitigation and Conditions of Pregnancy**

Recommended prevention of T2DM after GDM pregnancies includes healthy diet, regular physical activity, breastfeeding, and timely screening (O’Reilly, 2014). The prevention potential of lifestyle modifications on diabetes risk is based on robust data from the Diabetes Prevention Program (DPP). The DPP Trial was a randomized clinical trial of over 1000 participants with prediabetes where intensive lifestyle management decreased incidence of T2DM by 58% (compared to 31% in the Metformin-treated group). Of note in the DPP, women with previous GDM had a 50% reduction in risk for T2DM (Ratner et al., 2008). Similar

lifestyle recommendations exist for prevention of CVD. It has been reported that more than 90% of myocardial infarctions have been attributed to modifiable risk factors such as vegetable consumption, physical activity and smoking status (Yusuf, Hawken, & Ounpuu, 2004). Early screening in primary care for conditions such as hypertension and prediabetes is also an important means of preventing the morbidity and mortality associated with CVD and T2DM (Wallace, Rico & Barrett, 2014).

An intervention model to address the chronic disease risk associated with conditions of pregnancy is the postpartum risk assessment clinic. The pioneer site for this model by Smith and his colleagues in Kingston, Ontario consists of a modified risk assessment, like a Framingham risk calculator, offered six-months postpartum, followed by a consultation with an obstetrician. A participant's individualized risk profile results and lifestyle modification recommendations are discussed. Patients who are deemed high risk are then referred for specialty support such as a cardiologist consult or cardiac rehabilitation clinics (Smith et al., 2013). This model has been replicated and extended in many sites across Canada; approximately 17 centers exist nationally as of 2019 (Dayan & Nerenberg, 2019). There are similar clinics in the United States and the United Kingdom as well. An environmental scan of these clinics revealed that they operate on several different models ranging from extended biopsychosocial care of 12 months duration to medically focused single visit interventions.

Commonly, all postpartum risk clinics use medical risk communication and health education as the core intervention strategies. Risk communication is used with the logic that this will motivate women towards lifestyle change and future screenings to abate the possibility of future disease. These clinics have low levels of engagement, particularly among low SES



women, which could be in part due to a lack of health behaviour theory and a lack of a nuanced understanding of risk in the context of women's lives informing interventions and research.

### **Perspectives on Risk**

The concept of risk is often simplified in medicine as a cognitive experience where one weighs the likelihood or probability that harm or illness will occur (Lloyd, 2001). It is considered in terms of the odds of a negative illness outcome occurrence and its severity (David, 2008). This medical-centric view of risk assumes that if probability of future illness or complications to an illness is communicated properly, then lay people will rationally navigate these calculable threats and adjust their lifestyle accordingly (Morden, Jinks & Ong, 2012). Much research exists that aims to better "communicate" this medical and numerical view of risk (Naik, Ahmed & Edwards, 2012). However, this simplistic view of risk ignores people's lived experience and meaning making when considering risk. It has been criticized for assuming lay people's construction of risk is inaccurate and in need of correction. It also assumes that people make rational, numerical decisions about their health risks, as defined by medical professionals, and act on them (Morden, Jinks & Ong, 2012). Furthermore, cognitive models of risk emphasize choice, which implies personal responsibility and blame (Loewenstein, Weber, Hsee & Welch, 2001). This view limits discussions about risk mitigation to individual behaviour change without considering how risk is understood by the individual on their terms.

When considering risk signals from pregnancy, the medical model's definition of risk reduces its location to the woman's body. There remains debate in the literature if pregnancy conditions are the cause of future chronic disease risk or are signals that illuminate pre-existing risk. Some researchers suggest that maternal vascular risk factors exist years before pregnancy (Neiger, 2017). Others associate these conditions and the future risk they impose with placental

malfunction, which indicates it is the pregnancy itself that poses risk (Neiger, 2017). The first argument supports the notion that risk exists beyond the woman's body. Social determinants of health such as income disparities and violence are important etiological factors that influence risk and could create these vascular conditions (Kreatsoulas & Anand, 2010). For example, evidence is growing that preterm deliveries and the delivery of small for gestational age babies are strongly associated with intimate partner violence (Sigalla et al., 2017).

There are, however, many alternative constructions of risk that have been discussed in the literature. The lay person's understanding of 'risk' and their health decisions is influenced by social class, current and historical context, intuition and emotions (Morden, Jinks & Ong, 2012). Lay people struggle to retain a feeling of normalcy in their lives, despite a health risk. They are aware that a probability does not mean an absolute and recognize, and likely have some experience, with the randomness of health conditions. The 'risk as feelings' hypothesis describes emotional responses to risk as exclusive from cognitive experiences of risk and are thus not influenced by probabilities (Loewenstein et al., 2001).

Risks of present-day life are also considered when individuals engage in risky health behaviours. For example, women consider the risks of not getting a break from their children or the risks of unwanted strong emotions when they consider smoking cessation (Graham, 1993 as cited in Morden, Jinks & Ong, 2012). Another example of every day "risks" could be the threat of social exclusion by staying in and cooking a home-cooked meal verses aligning with social norms and eating fast food with friends (Higgs & Thomas, 2016). Wilkinson (2006) argues that managing self identity, emotions and social relationships is central to living with the threat of illness.

Risk as a means of control is another example of risk conceptualization described by Morden, Jinks and Ong (2012). The concept of ‘risk factors’ (as opposed to immediate health risks) has been utilized by the state as a means of encouraging individualized responsibility for “self-management”. Putting the responsibility on the individual promotes consumerism and facilitates cost-cutting on social programming and serves to control citizens’ actions. This differs from a previous era where government policy implicitly encouraged citizens to care for each other while there remained an expectation the state would care for them.

Risk also exists *from* medicine. For example, a recent study in Toronto, Canada added to the extensive literature on systemic racism for indigenous people in Canada. The authors found that indigenous patients experienced discrimination, procedural neglect from providers and unmet healthcare needs in urban settings (Kitching et al., 2020). Historically and presently, there are risks associated with taking prescribed medications in pregnancy including congenital malformations, preterm labour and fetal developmental delays (Mulder et al., 2018). Induction of labour, especially when under 39 weeks gestation, also poses risks including Caesarean delivery and even neonatal morbidity (Kim, Choo, Han & Kim, 2019). HCPs are tasked with weighing the risks and benefits of medical interventions and do not always make the correct decisions.

Discussions about women’s increased risk has served as a starting point from which prevention interventions might occur. In a recent committee opinion article, The American College of Obstetricians and Gynecologists (2018) described the first 12 weeks postpartum, coined “the fourth trimester”, as an ideal time to communicate to patients about future cardiometabolic risk. However, the committee failed to comment on the content or method of these risk discussions. Risk is used as a motivational intervention to encourage behaviour change

in a variety of settings. For example, CVD risk is commonly communicated using the Framingham risk calculator. This calculator provides risk information numerically in a linear manner by summing up risk factors (Karmali et al., 2017). Despite its intuitive appeal, there is little evidence of its effectiveness in this context. For example, a recent Cochrane review of risk calculators as primary prevention agents for adults with CVD found inconclusive evidence for their efficacy (Karmali et al., 2017). Another study by Welschen et al. (2012) found that educating patients with T2DM and CVD resulted in more 'accurate' risk perceptions, but it did not change behavioural intentions or illness perceptions. One issue with risk communication in health care settings is its reliance on numbers and percentages to relay information. Previous studies have found that even well-educated patients have low numeracy skills (Naik, Ahmed & Edwards, 2012). It has been argued that beyond knowledge and risk perceptions, shared decision-making is often overlooked as an indicator of successful risk communication (Naik, Ahmed & Edwards, 2012).

### **Risk and Conditions of Pregnancy**

The current risk mitigation model for postpartum women assumes that communicating risk is an effective means of motivating behaviour change as a primary prevention technique. Postpartum risk clinics assume that by simply telling women to engage in health behaviour is an adequate intervention; but is risk communication enough? Preventative counselling for postpartum women after GDM pregnancies may not be hitting the mark to date. For example, Kim et al. (2007) surveyed over 200 women with GDM and despite the majority being able to recall counselling on lifestyle modification, there was no significant association with immediate behaviour change. How well women receive risk information, internalize it, and change behaviour is yet to be understood.

Engagement in these clinics has also been a problem. Unfortunately, attrition rates for these types of clinics are as high as 25-50% (Dayan & Nerenberg, 2019). In an evaluation of Smith's clinic, the team found that younger, smokers, and less educated women were least likely to attend these clinics (Nowik, Pudwell, & Smith, 2016). Furthermore, no-show rates for specialty clinics based on referrals from the postpartum risk clinics are even more dismal (Dayan & Nerenberg, 2019). The reasons for the lack of engagement by women in postpartum risk clinics are no doubt complex. It can be argued that perhaps pregnancy and early postpartum is not the most ideal time to be discussing women's future health risk. Women's lives are often dramatically uprooted with the addition of a child, and even more so with multiple children. On the other hand, women have far more encounters in health care during pregnancy than any other time in their adult lives. Therefore, attitudinal and structural barriers to involvement in postpartum services for this population need to be better understood.

It might also be argued that the social determinants of health, as evidenced by the demographics of women who do make it to postpartum clinics, remain a potent contributor to health care engagement and future health (Adler, Glymour & Fielding, 2016). As mentioned above, risk does not occur in a vacuum. Risk is unequally distributed in society. Despite a woman's circumstances, their interactions and experiences in health care, can be either harmful or helpful for their future health projections. Health care workers can more effectively address the social determinants of health by adequately assessing social situations, such as access to affordable food and transportation, before offering treatment plans. They can also aid in connecting patients to appropriate community resources. Furthermore, "alternative support figures", such as health care workers, can contribute positively to correcting previous emotional trauma and attachment issues (Andermann & CLEAR Collaboration, 2016). Attention from the

research community on attrition from postpartum risk clinics also misses the opportunity to focus on the strengths that women have in seeking support for themselves in their own way. The health care system can play an important role but needs evidence to better support women in accessing what they see as needed, based on what they do have some control over. Research often fails to provide important contextual information and fails to include target populations in the development of prevention interventions. How to provide this information and encourage buy-in from women remains unclear.

Women's thoughts about chronic disease after pregnancy conditions is an under-studied area of research and often considered from a medical perspective of risk. A recent survey of women's views of CVD risk after pregnancies complicated by hypertension found that women with severe conditions and preterm deliveries had heightened awareness of future risk and were more 'accurate', in their medical view of risk, in their depiction of the implications of that risk, including myocardial infarction and stroke (Traylor, Chandrasekaran, Limaye, Srinivas & Durnwald (2015). Previous studies have analyzed risk perception and found that even when women are aware of their heightened risk, many do not believe they themselves will get the future condition. For example, one study by Kim et al. (2007) found that although 90% of their sample with GDM knew the condition was a risk factor for future diabetes, only 16% believed they had a high chance of developing diabetes. This study represents an example of the constructed nature of risk perception. There remains a paucity of research on risk perception in women, especially in the Canadian context.

One area for exploration is women's illness and risk perceptions and how these views influence their views of the future and their current self-care behaviours. We can better understand how communication might be helpful for engagement in health-promoting

behaviours, when patients are ready and able to adopt these behaviours. Previous research has perhaps used inadequate frameworks to make sense of this phenomenon. Medically-framed research on risk is incommensurable with how women construct perceptions of risk in the context of their daily lives and histories. Few studies exist that explore illness perceptions for women in pregnancy and there are even fewer instances where studies have used health theory to broaden the discussion about health condition views and subsequent risk. For example, a recent study on perceived future risk following preeclampsia did not explicitly use theory and instead simplified participant discussions around awareness and knowledge of future risk (Brown, Waring, Robson & Waugh, 2017). A more recent study on GDM used the self-regulation model and theory of planned behaviour to guide inquiry about postnatal experiences, however other pregnancy conditions were not considered (Eades, France & Evans, 2018). Other studies have focused on women's knowledge of the chronic disease correlation to their pregnancy condition and implicitly assumed that knowledge translates into behaviour change (Seely et al., 2013). Studies often focus on barriers and facilitators to lifestyle change postpartum with little acknowledgement of perceptions of the conditions that precede and influence lifestyle change (Sandsaeter, Horn, Rich-Edwards & Haugdahl, 2019).

### **Present study**

For clinicians to communicate health information effectively, the above conceptualizations of risk argue that we must understand how patients construct personal representations about a health threat and behave in accordance with these beliefs (Kucukarslan, 2016). As such, HCPs must understand where a patient is at in order to engage in meaningful conversations about health. More broadly, intervention development and implementation need a

better picture to work from, one that includes the perceptions and beliefs of the women as well as their self and social context.

Women's CVD health outcomes remain inequitable and not well-researched. Evidence is robust on the link between pregnancy conditions and future chronic disease risk, yet engagement remains low for clinics that are meant to serve the population of interest. Much of the narrative on this topic is quantitative and lacks voices from the women of interest. Research to date on women's views of this topic often lacks theoretical framing and inquiry narrowly focuses on future risk knowledge or preferred intervention programs postpartum.

This thesis sought to take a step back from solutions and instead explore women's journeys of conceptualizing their health conditions in pregnancy, the risks they pose (or not), and how this influences their prioritization of health-promoting behaviours. In this thesis, I attempted to situate risk in the lay perspective. The lay perspective looks at the individual as an expert in their lives and encourages an integration of medical input into their day-to-day world. I was also interested in women's views of HCP influence and discussion about risk in both usual prenatal care as well as for women who engaged in a formal postpartum risk clinic. Qualitative interviews allowed for a deeper understanding of the lived experience of the women who have experienced a risky condition in pregnancy. The aims of the present study were:

- 1) To explore women's representations of pregnancy conditions and their associated risk.
- 2) To explore what engages these women to participate in health-promoting behaviours.
- 3) To understand how women experience both short and long-term risk communication prenatally and postpartum.



## **Method**

### **Design**

The present research used a qualitative design to illuminate the lived experiences of women and their pregnancy conditions, their experiences with the health care system and their interactions with health care professionals. This design allowed access to the experiences of women directly to generate rich data concerning their experiences, thoughts, and feelings about their conditions and their associated risk. Speaking to the consumers of health care, in this case women, also provided the possibility for a deeper understanding of the context in which they make decisions about their health. Furthermore, qualitative methods were used because there exists an abundance of quantitative data to support the link between pregnancy conditions and future chronic disease risk. The current literature makes assumptions that pregnancy and early postpartum are the ideal time for risk discussions to occur. There are often calls to action for health care providers (HCPs) to discuss future risk with women. However, the “how” to discuss risk is lacking. This study aimed to understand how women process, construct and respond to their health conditions and how this conceptualization influences their health behaviours. The research aimed to support practitioners’ reflexivity in their practices and their interactions with patients with respect to risk conversations. Ethics approval was sought from the Trent Ethics Board and approval was received on July 18, 2018.

### **Theoretical Orientation**

The philosophical view from which the present study is rooted is constructivist, with influences from hermeneutic phenomenology traditions. As this research project progressed, elements of critical health theory also influenced my writing, in particular, the interpretation and discussion of the analysis. Constructivist research sees the individual as a unique, complex

entity and looks for in-depth understanding of individual perspectives (Ponterotto, 2005). The end-product is not generalizable to other groups. Constructivism views reality as being held in the mind of the individual and influenced by one's social and historical context. Each person will therefore see and experience reality differently. Research that is rooted in a constructivist epistemology does not focus on individual thinking, but instead attempts to make sense of the context and structural conditions that permeate individual accounts (Braun & Clarke, 2008). A focus on the relationship between researcher and participant exposes a person's deep-rooted views of the phenomenon of interest, while also recognizing the influence of the researcher's perception of the person's experience. The goal is to understand the lived experiences of research participants of interest (Ponterotto, 2005).

Heidegger and Gadamer's description of hermeneutic phenomenology complements the constructivist approach as it recognizes the importance of language in human understanding, and the dynamic relationship between the part and whole in the interpretative process (Evans & O'Brien, 2005). This tradition also believes that a person's world view is heavily influenced by their circumstances. Individuals are free to make their own decisions, but self-determination is not absolute, our agency is not separate from social, cultural and political circumstances (Lopez & Willis, 2004). Phenomenology grounded in the Heideggerian-Gadamer tradition allows for a shift from a biomedical, positivist paradigm of knowledge acquisition and searching for one truth to highlighting mutually important, alternative ways of knowing and seeing the world. As described by Evans and O'Brien (2005), our lived experience is "inter-subjective, temporal and relational." A new understanding is formed that will sensitize others (in this case medical professionals) about a lived experience.

As a further complement to constructivism, my ontological perspective shifted during this research process to encompass a critical health lens. Critical theory recognizes that one's social context is not entirely constructed by the individual but is also influenced by present and past contexts and power structures that hold up certain members of society while preventing equal access to opportunities for others. Society is viewed as a poorly functioning entity, where many groups are competing for power and influence (Alderson, 1998). An example that is relevant to this research is the privilege from which health care providers are positioned in the world and in the health care context and how this influences interactions with patients. A critical theoretical orientation became more of a focus for me during the analysis stage of the present research study and will guide some of the discussion on future areas for research. Critical theory also coincides well with focusing on lived experiences of women, an oppressed gender, as opposed to HCP's perceptions of communication with patients. Bridging lay people's knowledge with professional knowledge is an important step toward emancipation in health care (Alderson, 1998).

### **Mid-Range Theory**

In order to make sense of postpartum women's perceptions of future risk, it is helpful to take a step back and aim to understand their interpretations of their health conditions in pregnancy from which risk perceptions are derived. Leventhal et al. (1980)'s common-sense model (CSM) was utilized to develop the interview schedule for data collection and considered during the analysis process. This theory aided in conceptualizing women's illness representations, in order to help with understanding what drives their health behaviour. This strengths-based model can function as a tool for describing the processes involved in the start and maintenance of health actions for dealing with illness threats (Leventhal, Phillips & Burns, 2016). It is viewed by theorists as a valuable summary for understanding how a patient's views

of their illness, and their subsequent interactions with their social and environmental world, affect their adaptation to health conditions (Benyamini & Karademas, 2019).

The CSM makes the case that health conditions are viewed as threatening and people will make internally rational decisions to reduce such threats, such as avoidance or partaking in diet changes (Kucukarslan, 2016). The theory argues that people first develop cognitive and emotional depictions of their illness based on concrete data (such as symptoms and communication from health care providers). They use these schemas to manage their illness and to develop coping strategies for uncomfortable reactions related to the condition (Benyamini & Karademas, 2019). Features of the mental representations of illness include “beliefs regarding illness identity, cause, control, consequences, and duration/timeline), possible treatments, and action plans” (Leventhal et al., 2016). It also includes emotional responses, which interact with threat representations. This process is self-regulatory and dynamic. People regulate their responses to threats and regulate their emotions related to these threats simultaneously. The success of one’s behaviours for managing illness threats are regularly appraised and adjusted over time (Benyamini & Karademas, 2019). This internal feedback loop is rooted and influenced by the social and healthcare system, as well as the larger cultural context (Leventhal, Phillips & Burns, 2016).

The CSM has been used in research to make sense of various illness experiences. For example, to better understand what drives health responses to influenza, the causal attributions and concrete symptoms helped to frame beliefs about vulnerability to the illness (Leventhal, Phillips & Burns, 2016). The CSM has been used to explore emotional and cognitive responses to various conditions and sub-groups to guide health promotion interventions. For example, Huston and Houk (2011) explored youth engagement with chronic diseases like Type 1 Diabetes

and Sickle Cell Anemia and compared perceptions across conditions and levels of disease control. The CSM has also been used to conceptualize coping responses and action plans of patients living with osteoarthritis, such as focusing on dietary control (Hale, Treharne & Kitas, 2007). The CSM has also been successfully used in the development of health change program interventions. A systematic review of CSM-informed interventions found that targeting cure and control perceptions improved treatment adherence (Jones, Smith & Llewellyn, 2015). Newer uses for the CSM in research have also been proposed to better capture the fluid nature of illness representations and predict behaviour change in the short and long-term (Leventhal, Phillips & Burns, 2016).

### **Context of the Study**

The first site for recruitment was a female doctor-led outpatient clinic that aims to reduce barriers to care for psychosocially high-risk women. Patients have access to multidisciplinary care including social workers, nurses with a specialty in lactation support and a dietitian. The clinic's team cares for women from early in pregnancy until 6 weeks postpartum. Patients are then referred back to their family physician for future well baby checks and primary care support. It is important to note that I work as the team's dietitian at this clinic.

The second site for recruitment was a specialist-led postpartum cardiovascular disease (CVD) risk clinic for people who experienced at least one condition of pregnancy that puts them at risk of future CVD. These conditions include gestational hypertension, preeclampsia, gestational diabetes (GDM), giving birth to a small for gestational age baby (SGA), and preterm delivery. Women are invited to attend this clinic after their discharge from the hospital via a letter that explains their increased risk and how the clinic can help. They are then encouraged to complete bloodwork and other clinical measures prior to a debrief with an obstetrician

approximately six months postpartum. The women who attend this clinic could have been exposed to one of many prenatal care providers in the area in which they live such as a midwife, general practitioner, or obstetrician. They also were referred back to their general practitioner for routine well baby checks and primary care needs at six weeks postpartum. Both sites for recruitment were in small Southern Ontario cities.

### **Sampling and Recruitment**

Women with a recent history of a pregnancy condition that puts them at risk of future cardiovascular disease (CVD) were purposively sampled and recruited from both sites mentioned above. The study took place between September 2018 and November 2019. The recruitment period and initial interviews took place between September 2018 and January 2019. The follow-up interviews were completed by April 2019. I was interested in the perceptions of women who had attended a formal postpartum risk discussion compared to women who just had usual prenatal care, thus participants were recruited from two locations, one where women were exposed to usual prenatal care and the second where women attended a formal postpartum cardiovascular risk clinic. This created a natural contrast in data and perspectives between the two sites. At the first setting, because of the clinic's mandate to serve less well-resourced women, we aimed to recruit psychosocially higher risk participants. Doctors and other allied health staff of the clinic were asked to assess first if their patients had one of the six possible pregnancy conditions, as well as their patient's mental and physical health status. See Appendix A for the letter to doctors regarding their role in recruitment. If their eligible patient's health status was stable, the doctors provided a consent form (see Appendix B) to sign that permitted the researcher to call and explain the study. Participants then provided informed consent for

participation in the study either in person or over the phone prior to the interview. See Appendix C and D for the information and consent form and the debrief letter.

As per our ethics requirements, participants from the second location were recruited via mailed letter (see Appendix E). One eligible participant requested to join the study after her friend told her about it, which allowed for the recruitment to spontaneously expand via snowball method. Participants were invited to contact the researcher by email or phone; women who met the inclusion criteria were then provided study information and gave informed consent via email and reviewed verbally over the phone prior to the interview. Inclusion criteria were: a pregnancy within two years of the recruitment period, ages 20-40, and having one or more of the six previously mentioned pregnancy conditions. Exclusion criteria included significant, unresolved mental or physical health issues at the time of recruitment and a loss in the most recent pregnancy. Women from each location were entered in a draw to win one of two fifty-dollar gift cards from local baby supply stores upon completion of the interviews.

### **Procedure**

Guided interviews were the primary data source. I expected that women's experiences might be emotion-provoking, so my committee agreed that the one to one interview would be a more appropriate means of data collection than focus groups. Interviews also allowed for the voices of women who were less articulate or confident to be heard sufficiently. Interviews were completed either in-person or over the phone, based on patient preference. Offering phone interviews aided in recruitment and we hoped it would encourage less resourced women to participate in the study. Less structure to the interview was an intentional technique to allow for women to own and elaborate on experiences and views of their pregnancy condition(s) that were most important.

In preparation for the interviews, I completed three pilot tape-recorded interviews with classmates prior to participant interactions. The piloting process was an opportunity to practice interviewing skills such as reflective listening and open-ended question generation, get comfortable with the technology required for recording, and to test and modify the flow of the interview schedule. My supervisor attended the pilot interviews and provided feedback to improve the quality of the interviews. The interview schedule was again modified for flow and quality of answers provided by participants after the initial two participant interviews. See Appendix F for the interview schedule.

The first interviews with participants were 45 to 80 minutes long. Women were asked about their pregnancy experience, their illness perceptions, their thoughts about risks associated with their pregnancy condition(s), and views of their health care team's communication about risk. Field notes were completed after each initial interview to record the essence of the interview, the setting, the tone, and other nuances that are difficult to record via transcription. I completed regular check-ins with my supervisor to increase my awareness of my personal views and their influence on the research. All interviews were transcribed verbatim and encrypted for participant privacy. Initial interview transcripts and field notes were read through and I made timely notes and comments in the margins to help guide the follow up interview schedules. I discussed this content with my supervisor, and we agreed on and highlighted points for clarification and elaboration to address in the follow-up interviews. We discussed each interview prior to the next and added to/ adjusted the interview schedule as questions arose or apparent issues with flow were presented.

Approximately two to three months after the initial interviews, guided follow-up interviews were completed. The purpose of the follow up interviews was to clarify points made



by participants during their initial interviews and to provide the opportunity for participant reflection and expansion on their initial thoughts and ideas. These interviews were an important form of member-checking to ensure women's voices was heard accurately and to prevent my researcher views from dominating the interpretation of the data (Birt, Scott, Cavers, Campbell & Walter, 2016). Other strategies for ensuring quality will be elaborated on in the Strategies for Qualitative Vigour section.

### **Materials**

The interview guide consisted broadly of questions about the women's views on their pregnancy conditions and their associated risk, and how this relates to health behaviours and risk communication with their health care team. Illness perception questions were developed based on Leventhal's (2016) Common Sense Model (CSM) of illness perceptions. The CSM was used to organize and provide structure to the interview guide. I expected that the CSM constructs would be a starting point for conversations about illnesses and risk but would expand beyond current theory on the topic, especially given the uniqueness of the sample's conditions. After the pilot interviews and initial participant interviews, two additional questions were added to the interview schedule to better access women's experiences with risk. The interview guide served as a starting point for conversation but often conversations moved away from the initial questions based on participants' priorities for discussion on the subject. I prompted for clarity and expansion whenever needed. I also intentionally used reflective listening and summarizing throughout the interviews as a means of member-checking and to build rapport with participants.

To develop follow up interview questions, the initial interviews were transcribed, read over thoroughly and notes were taken by both my supervisor, research assistant and myself. Questions were developed to clarify points made by participants, statements from the transcript

were read for participants to consider and expand on or adjust. Each follow up interview schedule was thus unique.

### **Qualitative Data Analysis**

The data analysis and process of reflexivity for the present study was structured around thematic analysis with elements of hermeneutic inquiry. Thematic analysis enables a researcher to recognize and report on patterns (themes) and capture rich detail within a dataset (Braun & Clarke, 2008). The analysis was iterative and attempted to understand the data as a whole and understand the meanings within it (Crowe, Inder & Porter, 2015). Hermeneutic inquiry involves the process of making sense of a text where there is an interplay between the part and the whole. To recognise the whole, you look to the part, such as a single word embedded in a whole sentence (Smith, 2009). This analysis of the subject matter is circular, it does not follow a linear progression of steps and instead moves between small chunks of data, back to the bigger idea, and back to the script again. This circular process of interpretation of the transcripts occurred with the help of my supervisor at multiple stages of the analysis and writing. Another important aspect of hermeneutics is the relationship between researcher and participant. This process of reflexivity about my interactions with participants and its impact on my meaning making will be elaborated below. I also aimed to understand my participants and their interactions with others while recognizing the women's contexts such as culture and history (Lopez and Willis, 2004).

The data was analyzed using qualitative analysis software "Atlas TI". Demographic data was first extracted from the interviews and organized. Interviews were then segmented into larger tracts of data that focused on my primary research aims. The first tract of data concerned how women perceived their conditions of pregnancy and the meanings they gave to these

illnesses. The next tract of data included references to interactions with health care providers (HCPs) including all forms of management. Because of the recursive nature of qualitative analysis, as described by Braun and Clarke (2008), where one moves between analysis, data gathering, and question development cyclically instead of in a linear manner, the research questions shifted to include not only long-term risk perceptions, but also short-term. In order to initially organize illness perceptions, transcripts were coded based on a-priori Common-Sense Model (CSM) dimensions. These dimensions were women's views on identity (symptoms and experience of the pregnancy condition), cause, consequences, timeline, treatment control, personal control, coherence, emotion and behaviours (Leventhal, 2016). In order to prevent narrowing the women's experiences to a pre-existing theory, I expanded the coding process and inductively coded all other aspects of the data related to illness experience and self-management that were not easily organized by the CSM dimensions. I aimed to focus on an account that was data-driven not theory-driven. I then inductively coded health care interactions. I focused on the wider social network and context from which the participant was coming from to further contextualize the coding process. For example, I asked questions about interactions with others, what the day was like when diagnosed and attempted to understand the women's lived experience in the context of daily life (Lopez & Willis, 2004).

Themes were developed based on prevalence of common experiences across multiple participants and based on the density of discussion of an experience within a single or a small number of participants (Braun & Clarke, 2008). Examples of "negative cases" that did not fit with others' views were also highlighted. Experiences of women from each location and across pregnancy conditions were also compared. Thematic analysis that is rooted in a phenomenological lens has been described as a process of interpreting and unearthing unspoken

meaning behind texts about lived experience (Sundler, Lindberg, Nilsson & Palmér, 2019). I clustered codes that were related and then developed a definition of the themes and sub-themes. Analysis consisted of a dynamic process back and forth between the entire dataset, the coded extracts of data and analysis of the writing being produced (Braun & Clarke, 2008). With the help of my supervisor, I moved back and forth between parts and the whole of the written text and questioned “what is being said?” and “what story is being told?” Noteworthy elements that captured the women’s views of their pregnancy conditions were highlighted and ultimately developed into themes (Evans & O’Brien, 2005). Themes were also generated based on their relevance to the research questions of interest. Quotations that represented the heart of the themes were pulled from the data to illuminate each theme and sub-theme. I made a point of pulling quotations from a variety of participants in order to ensure each voice was represented in the study. The goal was to gather a rich description of the dataset as a whole to make sense of the views of participants that is not yet well-known in the literature. I then went back to the literature to make sense of the dataset instead of allowing the current literature to limit my acknowledgement of the participants’ perspectives (Braun & Clarke, 2008).

### **Strategies for Rigour**

The present study used various intentional methods to achieve integrity and rigour. With the relatively recent re-emergence of qualitative research in health fields and psychology, and the creativity in which qualitative research is conducted, there is a need to maintain rigour in method and analysis. It has been argued that a redefinition is called for to make sense of what constitutes quality when it comes to qualitative inquiry. Utility and fidelity are both helpful to consider when assessing the rigour of qualitative work. Utility relates to how well the research design supports the researcher’s stated goals (Levitt, Wertz, Motulsky, Morrow, & Ponterotto, 2017).

The present study recruited from a client-base that is less psychosocially resourced to capture the voices of women who are often under-heard in the research. Also, because women were recruited in person by their health care provider, we hoped a more diverse sample might be willing to participate. I also considered context in planning the study, we chose from a group of women with usual prenatal care as well as a group with exposure to a pre-existing risk clinic. Furthermore, context was considered in the discussion as to the nature of the prenatal care they received and how that influenced the participants' meaning making. How well an analysis contributes to new areas of knowledge by positioning itself apart from previous work is also considered a measure of utility (Levitt et al., 2017). This study took a step back to understand pregnancy illness perceptions instead of just focusing on future risk perceptions, which have been studied.

Fidelity refers to the researcher's ability to remain close to the phenomenon under study while also being faithful to the participants' perspectives. Fidelity is believed to be foundational in qualitative work and equally important across epistemological positionalities of the research (Levitt et al., 2017). One way to ensure fidelity in the present study included follow-up interviews, which were a form of member-checking. The follow-up discussions gave participants the opportunity to learn about the data generated from their interview and adjust and/or build on their views. Member checking exists when a researcher seeks feedback from participants after some interpretation of data has taken place to ensure it is true to their views (Levitt et al., 2017). The present study design also built in multiple opportunities to attend to my perspectives of the data as the researcher and make it known (not set it aside) in the analysis process. I met with my supervisor regularly and discussed my views and how they influenced the data development and analysis and received feedback on how to maintain the perspective of

the participant as prominent. Perspective management and acknowledgement was intentionally utilized instead of bracketing, which is used by descriptive phenomenologists to remove one's biases from influencing the data. The act of bracketing assumes that there is one objective truth that the research is attempting to uncover, which does not align with my theoretical position (Lopez & Willis, 2004).

I also intentionally coded beyond previous theoretical constructs and coded as close to the data as possible in order to stay close to the participant views. Although my research schedule included questions that were organized based on previous theory, I asked questions in an open-ended manner with little structure so the data collected would reflect participant's realities and not be boxed into a pre-existing theoretical framework. As described in Lopez and Willis (2004) when theory is used in iterative inquiry, it should provide evidence that it does not serve to influence the narratives of the participants. For example, I asked simple questions like "What is gestational diabetes?" and encouraged participants to describe their meaning-making of their condition(s).

Building rapport with participants and attending to the researcher-participant relationship also served as an important method for fidelity (Howitt, 2016). I engaged in interview skills such as reflective listening and empathy to encourage patients to feel comfortable in sharing their true feelings on the subject matter. An additional encounter via follow-up interviews also served to build trust.

### **Reflexivity**

I engaged in reflexivity throughout the research process. I attempted to make known my assumptions and positionality from which I analyzed the data. Part of this work involved recognizing my own preconceived ideas and experiences and how they influenced my

interpretation. Going back a step, I aimed to make known how my perspective influenced the interactions and my summaries of women's perceptions in the interviews. Heidegger argues that one's interpretation of another's views is always influenced by one's own prior experiences. It has also been argued that sometimes the analysis of the text itself is the point where one's own preconceptions can be seen more clearly (Smith, 2009). Therefore, this process of uncovering one's own influence on the ideas of interest, in this case, the participants' views is also cyclical and constantly evolving during the data gathering, analysis and subsequent writing. My views were also dynamic, in that they changed with each interaction with the texts (Smith, 2009).

I focused on the story of the participant and made sure to reflect on my own positionality and experiences and my responses to the perspective of the participant. I wrote memos about my reactions to the data and shared them with my supervisor on a regular basis. One struggle I had was balancing my role as a researcher with my role as a health care professional. I work at one of the locations I recruited from as a Registered Dietitian (RD). I wondered at times if I should clarify things a participant said about GDM for example if it was not based on clinical evidence or save it for another time outside of the interview. I did not want to miss the opportunity to clear up health misconceptions but also did not want to influence the data generated by the participants. As a solution, I offered follow up sessions with participants from the clinic where I work who were interested in learning more about nutrition and risk mitigation outside of the research context.

I also wondered if my role as a RD influenced participant responses to be more aligned with what they perceived I wanted to hear, especially with respect to the theme "Blessing in Disguise". I wondered if my role as a health care professional further influenced the power dynamic in our discussions. I deliberated with my supervisor about this concern, and we felt that

despite my position, accounts from the women were authentic, based on the rich, detailed description and strong similarities across participants on this subject.

Furthermore, I noted that my relatively similar age and stage in life as the participants (I have a young son) facilitated rapport-building at times. Although I did not overly use self-disclosure, it did serve as an opportunity to connect with participants. For example, I could empathize with some of the challenges of maternity leave as it was not so distant in my past as well.

Finally, one area in my career as a RD that I am passionate about is the Health at Every Size (HAES) movement. I noticed my desire to discuss weight neutrality in health care when women in large bodies discussed their experiences. I spoke with my supervisor about this position and he helped to point out ways to avoid “leading” an interviewee toward a discussion that was not directed by them.

## **Results**

### **Participants**

The sample consisted of eleven women in total, five women from location one, who were exposed to usual prenatal care, and six women from location two, who received formal counseling about their pregnancy condition and its link to future cardiovascular disease. The age range was 28 to 37. Six participants had gestational diabetes (GDM), two had preeclampsia, one had HELLP syndrome (HELLP stands for: H- hemolysis, EL- elevated liver enzymes, LP- low platelets counts), one had gestational hypertension, and one had a small for gestational age baby. It is worth noting that one of the participants who experienced preeclampsia had a pre-existing chronic condition, Type 1 Diabetes. The women’s education ranged from high school (n=1), college student (n=1), college (n=5), Bachelor’s degree (n=2), and Master’s degree (n=2). All the



participants but one were in a relationship at the time of the study. Most participants had access to health benefits at the time of the study, except for two. We were able to recruit both primiparous and multiparous mothers. The number of children the women had ranged from one to three, with four participants being new mothers. One participant had a previous loss but not in her most recent pregnancy, so she was eligible for the study. Follow-up interviews were completed for ten out of the eleven participants. One participant did not complete the follow up interview despite several attempts to re-connect with her.

In the first theme I present how the participants struggled emotionally with initial pregnancy condition diagnosis, their subsequent involvements with condition management, and their perceptions of their condition symptoms and their conditions as they relate to their health identities.

**Theme 1- Lived Experiences of Risk- Women struggled with shock, fear, loss of control and uncertainty that conditions of pregnancy brought to their lives.**

This theme reflects the chaos brought into the women's narrative experience through the diagnosis. The women described grappling with complicated emotions and pregnancy expectations that did not go as planned. The Gestational Diabetes Mellitus (GDM) experience of initial diagnosis and subsequent management of pregnancy conditions differed from the experience of women with other pregnancy conditions, such as preeclampsia. Because the groups with and without GDM had very different experiences, I will present the two groups separately.

**Initial diagnosis experience- GDM.** The participants with GDM spoke at length about the emotional turmoil and day-to-day challenges they faced during their pregnancy. Some experienced the diagnosis with confusion and surprise, while others took it in stride, expecting

the diagnosis. Two participants were not even aware of GDM as a possible illness in pregnancy until their diagnoses. For these women, the test results seemed to be even more emotionally loaded. “I didn’t really know about it until I had it when I was pregnant!” (P11, GDM).

On the other hand, two participants were quite clear they would develop the condition and were not surprised to hear their test results. One participant did not report feeling emotionally upset about the information and was quite matter of fact. She was not surprised when she received the phone call with her test results. She also reported strong family history, so diabetes was not a new concept for her “I knew, even before I got pregnant, I knew I would get gestational diabetes, and I knew it would come back (P2, GDM).” Another participant was also not surprised to learn of her condition. She described her expectations prior to diagnosis “...I had a feeling I was gonna end up with it, I don’t know why, but so it wasn’t a big surprise to me...” (P8, GDM). This participant had also read about some of the possible risks in pregnancy for women in larger bodies and advanced age and found out that GDM was a possibility. So, her lack of surprise was at least in part because of her initial research on the topic. “...the side effects (of being an older mom) include gestational diabetes so I did a bit of research on it before I was even was diagnosed...” (P8, GDM).

**Emotions- GDM.** After their initial diagnoses, the women with GDM coped with the realities of day-to-day self-management of their conditions. The women learned to self-manage a disease that is influenced by lifestyle factors like food, activity and stress. The emotions experienced during the participants’ pregnancies were complex and intense at times. The women elaborated on feelings of stress related to managing the condition while still handling other life obligations. They also recounted fear and worry, shame, and self-blame. In response to the question: “what is gestational diabetes?” P10 simply replied “I hated it. The nine-month

pregnancy was like 9 years for me (laughs)”. Stress was a common experience for participants with GDM. The self-management of the condition wore on the participants. In particular, blood sugar monitoring multiple times a day and dietary changes were the primary challenges noted.

Many women felt personally responsible for the results of their blood sugars, not just the testing of the blood sugars. They felt a loss of control and self-blame when blood sugars did not respond to their lifestyle efforts “I just felt like I had failed. Um because I thought I could control it with diet.” All the participants with GDM expressed self-blame for their role in developing their condition. This self-blame experience will be elaborated in Theme 2. Participants reflected on the challenge of remembering to test two hours after each meal and establishing this novel routine.

I think I cried every day... it's a hard change...your body starts to withdraw from all this stuff that you're eating, you're not taking in all this sugar. I was emotional, I was pregnant, I was... checking my blood sugar every day so all of that on top of changing my eating was scary so I would cry...(laughs) (P6, GDM)

Fear was also a common emotional experience. The fear of risks to baby was shared by most participants in the sample, regardless of pregnancy condition. The fear of consequences to baby will be elaborated in Theme 3. Furthermore, P10 (GDM) described deep shame with her diagnosis “I just cried and called my husband and tell him everything and told him like I was ashamed of it and I told him not to tell anyone.”

**Initial diagnosis experience- other pregnancy conditions.** The participants with conditions other than GDM had very different experiences with their initial diagnoses and subsequent condition management (or lack thereof). Many women were unclear about their conditions when their diagnosis was first presented to them. Three participants even described

not knowing the specifics of their diagnoses until after their delivery. The women in this group moved from initial indicators of a problem in pregnancy to delivery very quickly. There was little time or opportunity offered by HCPs for self-management or participation in their condition treatment plan. This quick turn-around led to little opportunity for day-to-day management of their conditions. It seemed like participants were working in “survival-mode” until after baby was born, at which point they were better able to make meaning of their conditions. Common emotions across these participants were confusion, shock and powerlessness.

P4 described the risks she experienced from healthcare itself. She was misdiagnosed when she first presented to her health care team and was sent home, she had little memory of the pregnancy experience that ended in a loss from that point on. Like some of the women with GDM, P4 was unaware that preeclampsia even existed prior to her diagnosis “I didn’t know about preeclampsia, and I didn’t know about anything, and so when it happened it was just shocking, and I had no idea what was going on.” P5 also did not know about her condition prior to her diagnosis and did not learn of the name of her condition until postpartum. When she first presented in hospital she was admitted and delivered within a few days. She had no time to adjust to the condition or self-manage it:

It wasn’t clear like what exactly I did have. It wasn’t fully until my son was in the NICU and I was visiting him every day and they would introduce...I was there for rounds most days so they would introduce um...like my son and you know basically to get a little schpeal of why he’s here and whatever but it kind of was only then that I found out that he was there because I had HELLP and that’s why I delivered early. (P5, HELLP)

Another participant understood her condition as “indicators” and did not have a clear diagnosis until postpartum.

To me it was that I had indicators of that and I was far enough along that it was safe to induce labour and it wasn't until I read the discharge summary that it was sort of clear cut that it was actually diagnosed as preeclampsia. (P9, Preeclampsia)

Another participant (P7) described her diagnosis of Gestational Hypertension as “shocking”. It was her first baby and she did not know what to expect. Her first conversation with her health care provider was that her blood pressure was elevated, and she would need to be induced. She felt like the news came “out of nowhere” and she was not given an explanation as to the cause or what the actual diagnosis was. P9 also felt like she was not prepared for her preeclampsia diagnosis. She reported her blood pressure was fine throughout the pregnancy but then “it was kind of a flip of a switch so no indicator it was coming”.

P9, however, was not overly distressed by the news she had to deliver early. She noticed that her blood sugars (she had Type 1 Diabetes) were not behaving as she was told they should have at that stage of pregnancy, so she was a key player in her subsequent diagnosis of preeclampsia. “I’m Type 1 Diabetic, and towards the end of my pregnancy what prompted me to go to the hospital was low blood sugar.” Because she was already living with a chronic disease, her active self-management of her blood sugars was not new to her and she was clearer on the signs and symptoms of when things might be wrong.

Only one participant with a condition other than GDM (SGA baby) had advanced warning that there might be issues with her pregnancy. She described being told later in her pregnancy, about 30 weeks, that her baby might be smaller and that she would need regular scans to monitor his health. She had the most notice and was therefore sufficiently prepared when the baby was born that he was going to be small for his gestational age. This participant was matter of fact when describing her pregnancy experience:

Once she determined it was a smaller baby, he was uh, much more heavily monitored. So with normal pregnancies, you have an ultrasound at about 20 weeks or something and you usually don't go again until your due date but I went for pretty regular ultra sounds to kind of keep tabs on his growth and she kind of let me know that if she continues to be quite a bit small, we may end up in the future starting to deliver a bit early (P3, SGA).

Interestingly, P3 appeared to demonstrate emotional coping by reporting she was “not worried” at multiple times during the two interviews:

As far as complications go, I would say my complication was pretty minimal as opposed to some of the other a lot more challenging or dangerous risk complications that some people have so I wasn't as worried about it as some people might have been (P3, SGA)

She even went so far as to say that having a smaller baby was easier as a means of focusing on the positives of her situation.

...the way I kind of looked at it is that as long as he's healthy and everything is good on his end and developmentally and if he's little, I'm not really worried about it, and well, if you have a little baby it's a lot easier... (P3, SGA)

A major part of the women's experience with their conditions was preparing for early induction. The women recalled little discussion with their care providers as to the reasons and pros and cons of their treatment plans. This lack of conversation and patient-centered decision-making will be elaborated on in the Medicine's Role in Risk section of the analysis. How women experienced their conditions physically will be discussed next.

**Symptom identity-GDM.** Three women described physical symptoms of their conditions. Each of these examples represent the women's lived experiences of GDM 'symptoms' that do not align with medical views of symptoms of GDM. These experiences

likely shaped the women's views on efficacy of their condition management and their perceptions of short-term risks associated with their conditions. One participant described sleepiness and excessive thirst as an early warning sign of GDM, "well I knew because for about a week every time I ate, I could not stay awake. And they always say a sign is that you're always thirsty, but I was so lethargic, so I couldn't even deal with the thirst" (P2, GDM). The same participant also attributed fatigue after eating to elevated blood sugars. P11 (GDM) described her physical experiences with what she described as low blood sugar. She felt she could rely on body sensations instead of blood sugar monitoring at times. "Um each week I tried to be as active as I can and monitor my sugar but of course sometimes I can't. I can feel it in my body, my sugar is getting low and I have to eat." Another participant, P10, described her cravings as part of her symptoms of GDM. She recalled in her previous, non-GDM, pregnancy she craved sour tastes to ease her nausea, whereas the GDM pregnancy she craved sweet:

I was most towards the sour things, like I liked lemons...that was the thing that helped me, the nausea go away and the morning sickness but with this one I hated lemons and I was so moving towards the sweet things like donuts, sweet tea, pops, ice creams...

Others in the sample did not discuss symptoms of GDM.

**Symptom identity- other conditions.** Participants with other pregnancy conditions seemed to understand their conditions as medical indicators that were associated with their conditions of pregnancy. The women seemed to be disengaged with the felt sense of their conditions and relied on medical language to describe the conditions. Very few physical symptoms associated with these conditions were mentioned. For example, one participant named high blood pressure and protein in her urine as indicators of preeclampsia. P5 could reiterate some of the indicators of HELLP syndrome- she recalled that her platelet count was low

and that it was a “spin-off of preeclampsia.” She also thought of other indicators that she had not put together during her pregnancy but reflected on later. She had high blood pressure for her but not overly high and she had intermittent swelling in her feet “I remember thinking it was high but um...for a pregnant woman it’s not...it’s kind of normal. But if I do end up having another pregnancy, I will be aware that that is a high blood pressure for me.” P7 did not have any physical symptoms for her high blood pressure “I didn’t actually feel any symptoms of my hypertension, so it was really (laughing), I had a really high blood pressure and I felt great!” As mentioned above, P9 noticed she had more hypoglycemia that was harder to treat, which was the symptom that precipitated her seeking medical attention. The women’s symptoms, and often the reason for seeking medical help for these conditions initially, were often not in fact symptoms related to their conditions and instead a maternal instinct that “something was not right”. For example, P5 was admitted for HELLP but initially went to the hospital because of heartburn symptoms “I had been having some chest pains and things so I wasn’t sure what was going on and it ended up...and we found out the day I delivered that it was reflux.” These experiences demonstrate the power of the women’s intuition in aiding their medical teams in diagnosis of their conditions. Trusting intuition will be elaborated in the Medicine’s Role in Risk section.

**Health and personal identity-GDM.** The women’s sense of personal identity about their health coming into the pregnancy was either shifted or affirmed with the news about their pregnancy conditions. Some participants felt more confident in their health and lifestyle decisions prior to pregnancy than after. It seems that the women with GDM all had preconceived ideas about diabetes as an illness and so their health identity seemed to be shifted in a more dramatic way than the women with other pregnancy conditions. Two participants described feeling more confident in their health prior to their pregnancy condition:



I thought I was taking care of myself but I wasn't...I was confident in my self-care and I had a very good opinion of myself and my self-view but my body had changed afterwards where I realized maybe I wasn't, I wasn't as um...well...I wasn't as good as I thought I was (P6, GDM).

On further reflection, P6 also described her parents as not being healthy people. They seemed to associate healthy behaviours with not living life to its fullest. She said she also defaults to this worldview and seems to have worked on adjusting this thinking so she can continue to work towards lifestyle change:

I think too I was raised in such a fashion that, like my family, my parents also didn't care about that stuff... so it's just in my nature to not have it on my radar too... like my mom never took care of her diabetes ever (laughs) and my parents like, my dad says I work hard to play hard so he, he eats what he likes. He binge eats, he drinks, you know, like, they're not health-conscious people by any means, and they enjoy their life like that, like my dad's philosophy, he always jokes 'I'll be dead before I hit the floor'.

P10 was also more self-assured about her health prior to her GDM pregnancy because she assessed herself as healthy and did not have GDM in her previous pregnancy:

I thought I was in pretty good shape and then, the diabetes, with the diagnosis of the diabetes I thought that ooh, I was wrong all the time and it's... if I was healthy enough, I wouldn't get diabetes...I don't see myself as a healthy person anymore.

Another participant discussed her high expectations of pregnancy and her desire for an optimal self-image as a pregnant person. Prior to pregnancy, P8 was used to feeling unhealthy and feeling susceptible to illness, in fact she reported that she often preoccupied herself with thoughts of being unwell. However, in pregnancy prior to her GDM diagnosis, her identity shifted to

feeling quite good and not being as worried about her health. The news about GDM was therefore quite challenging to her pregnancy self-image but not her pre-pregnancy self-image:

When I got gestational diabetes it was kinda like a blow in the sense that these are supposed to be our healthiest times to carry a baby and this is kind of a hit to that so...but yeah before the gestational diabetes I wouldn't say, my pregnancy was this little pocket of time where I felt really healthy and I wasn't worried about my health. But before my pregnancy it was always a concern and after it was a concern again (P8, GDM).

These experiences of feeling less healthy after diagnosis of pregnancy conditions represent another example of how women were disempowered by their medical experiences. This rattled sense of self-confidence could have ramifications for health decisions in the future.

**Health and personal identity- other conditions.** Most of the women with conditions other than GDM were confident in their health before and after their pregnancies. Their views of their conditions seemed to be less “loaded” than the women with GDM and they did not seem to overly identify with them. Specifically, they saw the conditions as transient and temporary without the same personal shifting that the women with GDM seemed to have. As mentioned above, many women described the conditions as “coming out of nowhere”.

P3 did not even identify with the terminology I used as researcher calling her small for gestational age baby a “pregnancy condition”. She repeated on more than one occasion that her baby’s size was simply about fat mass and had nothing to do with development. “I don’t really even think of it as being a condition like someone having like preeclampsia or something like that um...I just kinda looked at it like he is really little you know cause it didn’t really affect me.” P7 also felt confident in her own health and described feeling betrayed by her diagnosis of

gestational hypertension, "...as far as my health, it was, I felt like, maybe I felt like...um...I don't know if this is right but I felt betrayed or I didn't understand why that had happened."

In sum, the women's initial diagnosis experiences and subsequent self-management (or lack thereof) was quite different for GDM compared to other conditions of pregnancy. The GDM group seemed to play a more active role in their treatment and grapple with the day-to-day stresses associated with the additional duties for blood sugar control, whereas the other conditions like preeclampsia came up quickly and the women were a lot less involved in their treatment. This group experienced shock and disempowerment during their condition journey. Both groups experienced little physical symptoms with their conditions, which had various implications on their illness perceptions. The women's personal health identities seemed to be shifted for some as a result of their pregnancies, whereas others were not influenced by the pregnancy experience. In the next section I will present the women's reflections on the cause(s) of their pregnancy conditions, their views on personal agency in reducing risk, and their behavioural and emotional responses to these views.

**Theme 2- Cause and Self-Blame- Where conditions were attributed to lifestyle, women felt a sense of personal responsibility and self-blame.**

The women with gestational diabetes (GDM) attributed the cause of their conditions to family history, personal lifestyle decisions, and, in some cases, chance. The women with other pregnancy conditions saw the cause of their illnesses as primarily unknown or chance alone. These participants did not take personal responsibility for the conditions. A common emotional response to the causal attribution that GDM is primarily a lifestyle issue was self-blame. The experiences of women with GDM will be presented first and the women with other conditions of pregnancy will follow.

**GDM- cause.** Many participants with GDM spoke about the role family history played in the cause of their conditions. Participants were aware of the genetic link to gestational diabetes and reported family history as a probable contributor to their conditions. “For me, I have a history of diabetes in my family, so I think it was probably, I was at high risk as it was...” (P6, GDM). Another participant was well-prepared for the possibility of a GDM diagnosis because of her extensive family history with Type 2 Diabetes. “Um...genetics. Everyone in my family had diabetes, like my parents, my mom had really bad diabetes. I had aunts and uncles with diabetes...(P2, GDM)”

Most participants felt strongly that even with genetic predisposition, lifestyle and age were the main drivers of their conditions. For example, P10 reduced the reason for her GDM to the type of breakfast she typically ate stating “...the thing is for my own case I think getting in the habit of eating one type of breakfast every day with that sweet tea that was the problem you know...” This assessment seemed to be quite black and white, as in this one behaviour was the only real cause of the condition. P11 also described her life circumstances as at least part of the reason she was diagnosed with GDM. She worked night shifts, ate all night, and didn’t do a lot of strenuous activity:

I think what happened was early in the pregnancy I worked nights and I eat what I want, I eat like, you know what I mean? Like I eat food and like there was no limit, especially night... so yeah I think that’s a big factor and of course I wasn’t active.

Another participant also summed up the cause of her condition to her eating habits. “I probably indulged a little, you know... I was kinda eating all the ice cream in the world! (laughs) I think it was more my lifestyle (P8, GDM).” Social and medical messages that diabetes starts with individual lifestyle choices likely influenced the women’s causal attributions of their GDM.

In later reflecting on their condition of pregnancy, three participants became ambivalent regarding their personal role in the development of their conditions. They transitioned from focusing on lifestyle behaviours that they were responsible for and noted the element of chance in their diagnoses. They seemed to feel two ways about their role in the development of the condition, leaving them unsure of the true cause. For example, P8 noted her friend's poor lifestyle decisions and how she did not experience ill health in pregnancy. She described the unfairness of the situation:

I have a friend that has a lot of the same circumstances, same age, really terrible eater and she was totally fine for the pregnancy whereas I am a fairly healthy eater, everything we eat is from scratch and we cook at home, uh, so yeah, you know, I don't understand why I ended up with it and she didn't.

Another participant compared her first healthy pregnancy to her second GDM pregnancy as evidence of chance. She mentioned the randomness of developing the condition. "...it happens for some pregnancies, it doesn't happen in some other pregnancies, it happens in some women, not others (P10, GDM)." The above examples demonstrate that even with 'risk factors', the women experienced and recognized the randomness of their health conditions and their associated risk.

**Other pregnancy conditions- cause.** The women with other conditions of pregnancy did not see themselves as responsible for the development of their conditions. The women mostly felt that the cause was unknown, or it was simply because of chance. For example, P3 described the randomness of her baby's small birth size. She was told by her health care team that they did not know what caused her condition of pregnancy that resulted in a low birth weight baby. She also did not bring any sense of personal responsibility for her birth outcome.

As far as I know, they don't know what causes it...I don't know why uh, he was low birth weight. I mean if I have another one it could be the same thing, or it could be a totally different case. We could end up with some...12-pound baby I don't know, hopefully not (laughs) so yeah I mean, who knows really...

Two participants pointed out that they did not seem to fit into the risk factors for preeclampsia or gestational hypertension that are usually described in patient education. They too sensed the unpredictability and unfairness of their conditions.

I didn't fall in any of it, like... what's listed for pre-eclampsia. I literally did not gain 15 hundred and 20 pounds.... I don't exercise regularly, but I have dogs, we go for walks, um...and...I'm not a crazy healthy eater but I don't eat horribly um...so I didn't think I was in too bad of a shape and my family history's really good (P4, Preeclampsia).

Only one participant in the non-GDM group had a clearer understanding as to why she developed a condition in pregnancy. P9 had a different perspective on the cause of her preeclampsia because she already lived with the chronic condition of Type 1 Diabetes. She was aware that this condition is a risk factor for preeclampsia stating, "My understanding is that I was at risk already because I already had type 1 diabetes." Perhaps this participant had a clearer understanding of the medical use of the term 'risk factor' having been exposed to a medical team regularly since her diagnosis with Type 1 Diabetes.

**Self-blame.** Participants with GDM experienced self-blame as a result of their view of personal responsibility for the condition of pregnancy. As discussed above, during pregnancy the women with GDM believed their decisions and actions were, at least in part, the reason for their condition in pregnancy. The socially constructed view that they had control over these

lifestyle decisions such as their age of conception and body size led to extensive experiences of self-blame. Elements of self-blame came up in 100% of the GDM sample.

I felt like when I really thought about it too, I felt really guilty, like it was my fault that I had it and you know now my baby had to deal with me, you know, deal with the consequence of it (P1, GDM).

Although P2 was aware of her widespread family history with diabetes, she also felt her diagnosis of GDM was caused by her lifestyle decisions. She felt she was responsible for her body size. "...I think I thought it'll happen any ways and I'll deal with it when it happens, which isn't the healthiest choice but if I made healthy choices, I wouldn't be overweight to begin with right?" Beliefs about the effect of age at conception on health also led to self-blame.

...you just wanna have a pregnancy like everyone else does, you don't wanna, you know. And I know it doesn't matter all the time, because skinny, young people end up with gestational diabetes or preeclampsia, but you feel like you kinda brought this on yourself just by being old (P8, GDM).

Interestingly, P8 took on her age for having a baby as entirely her decision without mentioning the age of her partner. This again represents a socially constructed view on women's age being a risk, whereas men's age not relevant.

As discussed above, P10 blamed herself for her food choices, "I felt guilty somehow, as I said, because of my habits of eating that I had. Sweet tea, rice, all those things that have sugar in it, lots and lots of fruits, watermelons, I love, cantaloupes, I love". Self-blame was particularly evident when women's efforts to control their condition were not effective and their treatment plan became initiation of insulin therapy.

...I just felt like I had failed. Um because I thought I could control it with diet. My daytime numbers were all great so I thought I could, so I thought I was doing something wrong to have the fasting ones be um...out of target (P8, GDM).

P10 also felt responsible for the need to start insulin. She felt she was not able to adhere to the “diabetes diet” and that was the reason she was required to take insulin. She described herself as a failure when it came to diet modification “And then, you know when I, when we figured out that diets I can’t go on, I can’t reduce that sugar, that blood sugar, I had to inject insulin.” These participants, in many ways, blamed themselves for their diagnoses but interactions with health care providers and personal experiences seemed to moderate their self-blame. This will be further addressed in the section on health care provider communication.

Causal attributions in turn influenced the women’s views on their susceptibility of the chronic diseases associated with the pregnancy conditions. The participants’ perceptions of cause influenced their sense of susceptibility to future conditions associated with their pregnancy conditions.

**Perceived susceptibility to future risk.** Family history influenced some participants perceptions of their susceptibility to future chronic conditions like diabetes and cardiovascular disease (CVD). Some participants saw themselves as at risk for future conditions prior to the diagnosis of their condition(s) of pregnancy because of their family history. For example, one participant discussed her awareness of her family history of cardiovascular disease (CVD) and her susceptibility to this condition ten years prior to her pregnancy condition. “I do know that I have a history of that in my family so even before being pregnant that always kind of um...it’s always been a risk for me or always been in the back of my mind...” (P3, SGA Baby). This uncertainty left P3 not overly concerned about her own future health but did mention feeling less



confident about the potential risks for future pregnancies. She mentioned that the cause was not heritable, and it was simply a malfunction of the placenta. Her language seemed to be removed from the experience, to some extent, she described the placenta as “the placenta”, not “my placenta”. Others, because of their lack of family history, were less able to see that they were at increased risk in the future. One participant felt less able to understand how she had a higher chance of developing diabetes when she had no known family history of T2DM. This influenced her sense of agency in prevention. Her sense of personal control in prevention of future disease seemed to be wrapped up in contemplation as to if she was personally responsible for developing the condition.

Well... it's just weird too just cause, like, in my, both sides of my family, nobody, we don't have a history of diabetes at all...I don't know, like if it's something you get it from not eating properly or not being active is that one of the causes or is it as you get older the insulin your body produces is not working as well anymore, so I guess...I kind of feel like, I don't know how to prevent it if it's something that depends on your pancreas. Like if I were to eat super healthy and exercise and all that, later in life, do I still get it? It's just kind of like is there a way to prevent it or is maybe later on if it happens it happens...? (P1, GDM)

The above quote displays that P1 wondered if her future risk projections are, in fact, modifiable if it is not only caused by eating poorly and not being active. She seemed to process the message from health care providers that the condition is not her fault and sometimes just the nature of the physiology of pregnancy but then questioned her agency in prevention of diabetes.

Another participant (P4) seemed ambivalent about her future risk; one interview she shared her debilitating fear of CVD, she had never thought about her future self until the

pregnancy. After she learned about the link between preeclampsia to future heart disease risk, she reflected on her subsequent pregnancy “I could have been setting myself to not walk out of this”. She had the impression she might die from her next pregnancy. She was not thinking about long term risk, instead about risk of dying of a heart attack in her next pregnancy.

Whereas in her follow up interview she reported feeling “cocky” about her health because of her relatively healthy family members. P11 believed that GDM happens at random but only people with family history will develop Type 2 diabetes later in life. So, for her, with family history, she felt she was highly susceptible to this future chronic disease.

**Behaviour change as a response to casual attribution and future risk perception.**

The participants’ views on cause of their conditions influenced their enactment of health behaviour in different ways. For example, two participants were aware of their extensive family history prior to pregnancy, yet they used this information quite differently. One participant (P2) was aware, yet life circumstances and personal factors did not lead to her adjusting her lifestyle to prevent future disease. She reports feeling that she was aware that it would happen, accepted this, and felt it was easier to deal with it as it comes instead of actively trying to prevent it. “I think I thought it’ll happen anyways, and I’ll deal with it when it happens...” P2, GDM.

P3, on the other hand, recounted significant behaviour change ten years prior to her pregnancy and on-going maintenance to present time in order to prevent future risk. P3 also reported in her follow up interview that her motivation to keep her lifestyle in check currently was more related to her family history than her condition of pregnancy. The condition, however, served as a reminder for her. P5 also felt that she kept her lifestyle in check at least partly because her grandfather had significant heart disease. P6 also spoke about her family history but

found it was the pregnancy and future risk discussion postpartum that was the catalyst to mobilize her into action for her health.

I always knew the family history was there but it never really triggered me to act on it at the time but once I had the gestational diabetes myself and it was directly related to me that's when it became more of a factor so now it has an impact on me making those changes but before I was pregnant it didn't really impact me at all and it didn't matter as much if that makes sense. (P6, GDM)

P4 described being well-aware of her risk yet described her emotional coping instead of behaviour change when she thinks of future risk associated with her preeclampsia pregnancy:

I get so freaked out when I read it like the first post, I read it and I immediately went to panic and I had to stop and put everything down and like push everything to the back of my mind as possible, I know its stupid, its just like every time it comes up it scares the bejesus out of me and I know I need to make changes but its just like I get scared... I just wanna forget about the future risk or that the possibility is higher now.

The women's causal attributions for their conditions in pregnancy can be summarized as family history, personal lifestyle decisions and age, not known, or chance. Views on cause were not entirely clear for the participants and many women felt ambivalent as to their personal responsibility, especially after interactions with their health care teams. The women's agency over their treatment decisions was swayed. The women responded to their perceived role in the development of GDM, in particular, with strong feelings of self-blame. Many women also responded to their pregnancy conditions and/or previous understanding of their susceptibility by making lifestyle changes.

**Theme 3- Baby First- Irrespective of condition, baby’s health – present and future - was first and foremost in the mother’s mind**

In contrast to other themes, an element that was common across cases, regardless of pregnancy condition, was “Baby First”. When considering their health conditions and the impacts, the primary concern for most women was for the health of the baby. As one participant described “It’s natural instinct for a mother to put herself last and her children first.” Baby was a focus both in the short and long-term when participants considered the severity of their condition, consequences of their condition and discussions about future risk. The mothers’ views on consequences to themselves were less of a focus and will be elaborated on at the end of this section.

**Severity.** Views on severity of pregnancy conditions were influenced by the perceived risk to baby only. For example, P1 described gestational diabetes (GDM) as stricter than other types of diabetes because her baby was involved:

I was told it was closer to the baby and we wanted to stop the growth being so big and the horror story... so just kind of overall it seems to be in a way more dangerous and more uh... more strict than any other, like a regular diabetic.

The same participant also used interesting imagery in her understanding of baby’s involvement; she pictured the risk of macrosomia as “the skin stretching” and “fluid getting inside the baby”. P11 (GDM) focused on the potential impact on baby as the only consequence if the condition was not well-controlled. “The baby could have like a high weight when he is born and of course the sugar level of the baby you know when the baby is born can be monitored as well and if the 24hr range if it goes down and um... yeah.” P3 (SGA Baby), on the other hand, did not see her pregnancy condition as overly serious because she was told it would not

have an impact on her baby's development "I didn't look at it like a huge health concern, and I was also told that low birth weight isn't an issue of them nor developing properly so I didn't have to worry about anything on that end."

**Consequences.** Others reflected on the health impacts to their babies as reflective of their overall success with their condition. P2 saw the size of baby as an indicator of her successful pregnancy with GDM. Her baby's size was a main concern for her prior to her delivery. "It worked really well for me... my baby was not ginormous... she could've been too big to get out, but she was 7'10." Another participant (P8) listed her criteria for a successful pregnancy with GDM and they were all related to baby's short-term health outcomes. "I think probably at the end of the day I had a really healthy baby boy; he was fine, his sugars were fine and everything was fine with him so... um, I think it was worth it." A consequence to baby of concern from one mother was the stress of the pregnancy condition on baby's mental health:

I was worried that this thing [early induction] actually have side effects on his mental health...and again all the doctors told me there's no effect on the baby other than the size, but I still had a feeling that something might happen to him...(P10, GDM)

And finally, P2 was quite upset that her inability to breastfeed was another consequence to baby from GDM "you know what also upset me is that it affected my ability to breastfeed."

Furthermore, many participants reflected on their babies' immediate risks after labour and resulting time spent in the neonatal intensive care unit (NICU). This immediate consequence to baby seemed to be the most profound in the interviews. P5 described her son after her pregnancy complicated by HELLP "at that point I was able to go and see my son in the NICU, so that was, that was pretty hard seeing him uh...all kinda hooked to wires and stuff and not really know what to expect."

**Health-promoting behaviours for baby.** The women also reflected on their personal health behaviours presently and into the future and how they relate to their baby and other children. Although participants focused on consequences to baby and future babies, they also reflected on their own health and how it can serve their children. They discussed role modeling healthy lifestyles and focusing on their vitality for being optimal parents. Many participants viewed their future health as important in order to live longer, fuller lives for their children. P3 (SGA baby) stated "...when I think of sort of changing my lifestyle, living healthily it's to some extent for my son, and it is for me as well, but it's for him that I don't die earlier than I need to because I don't want to leave him without a parent...". Also, some women described their desire to better manage mental health as parents because they did not see it as acceptable to cope in the same way as they did before.

I didn't wanna be sitting at home being anxious while taking care of him so I'm gonna do what I have to do to make myself feel better whereas before it was like, I'll just sit and hibernate at home and just feel crappy until I don't anymore and start to cycle again, so health care wasn't as a big priority as it is now (P8, GDM).

Other participants described wanting to have enough physical strength and energy for their children. P1 reflected "...when he gets older and running around, I want to be able to run with him...". P9 also described her desire to be healthy enough to keep up with her daughter:

I hope she is just a busy little bee like most kids are and I want to be able to have energy to do things with her and not worry and not feel like exhausted all the time or you know to try to find ways to calm her down if she wants to do those things I want to be able to do those things with her (P9, preeclampsia).

Furthermore, P2 desired being a good health role model to prevent chronic disease for her child. “...I want to provide good habits to teach her because I’m sure she’s gonna be at risk because of genetics, right? So, I want her to grow up knowing, you know?” Not only were the women’s health-promoting behaviours prioritized based their impact on their children, the women also focused on how their future risk impacted future children.

**Baby in future.** It seemed that future risk related to the conditions of pregnancy were prioritized by the women as first- concern about future pregnancies (for those who wanted more children) and second- concern for themselves and their future risk. For example, after their deliveries, when participants were invited to the postpartum clinic to discuss their risk for future chronic disease, five out of six participants described their main motivation for attendance was to learn about future pregnancies. The women were interested in their own health only as it impacted their ability to try for another pregnancy. P4 (preeclampsia) described her mind as “muddy” at the postpartum clinic and was mainly only focused on steps for her next pregnancy. “...my focus was not where it should have been like my focus was ‘can we get pregnant again’ and that’s it.” Several participants felt glad they attended the postpartum risk clinic, particularly as it related to their risk mitigation for health conditions in future pregnancies. Taking Acetylsalicylic acid (ASA) early in future pregnancies was noted by three participants as a secondary prevention option. As P7 mentioned “I’m glad I had the follow- up with the clinic again because I wouldn’t have known I should be at a certain gestational age be taking uh, aspirin?” Consequences from the pregnancy conditions on the mothers were also discussed and will be elaborated on below.

**Consequence- Future risk to mother.** The consequences of pregnancy conditions on the mother seemed to be far less of a focus, and less emotion-inducing, than consequences to

baby. The women who discussed their own future risk of chronic disease seemed to consider it as something that will happen way off in the future.

**Timeline.** The women mostly saw their conditions as “over” upon delivery and did not see them as chronic conditions. As P11 stated “it’s passed now.” P8 discussed future risk of diabetes as something that will happen “...later in life”. It seemed that later in life did not mean an immediate concern. Another participant also discussed her fears of her health as she “grows old” but was not concerned about her immediate health. “...I’m stressed about when I grow old and what’s gonna happen” (P10, GDM). P1 was ambivalent about her role in future risk because she did not feel she had enough information, “like I haven’t figured a general age that is kicks in.” Physical symptoms as an indicator of a health problem were also discussed by three participants with respect to future risk.

**Physical symptoms.** P10 described that she mostly perceives her health as how she is feeling “I didn’t check to see how it affected my total health because I just go with my feelings and how I feel about it.” P11 stated that she would follow up with her health care team if she felt symptoms of high blood sugars “...you know you have to be aware of the symptoms to be diabetic um... um... if you feel the symptoms...you can call your doctor and get it checked.” P3 (SGA baby) reported that her risk of CVD seems quite low right now and it will feel more serious when and if she develops symptoms or high blood pressure. She was also not surprised to learn she was in a low risk category for future heart disease because she doesn’t have high blood pressure. When asked what would make her risk feel more serious, P3 replied “I think if I had issues with high blood pressure or symptoms.”

However, two participants seemed to see the imminence of their risk. When P2 reflected on her mother’s premature death during her pregnancy that was related to CVD, she stated that



her health is also more of a priority based on her GDM pregnancy “...everything happens for a reason. The universe was telling me, like you’re gonna end up like your mom if you keep going down that road.” P6, after being counseled at the postpartum risk clinic, learned that she met the criteria for metabolic syndrome, and this was the catalyst for major lifestyle change. She saw the immediacy of her risk. “...I didn’t want to have a heart attack at 35 and found out I could have done better since...I knew better so, that’s the motivator for me” (P6, GDM).

The women focused on baby, particularly when considering the short-term risks associated with their pregnancy conditions. They described consequences and outcomes for baby when considering the severity of their conditions and many women felt the condition was transient and resolved after the birth of their babies. Their conditions seemed to motivate women to consider their health mainly for the purpose of role modeling for their baby’s future health or “sticking around” for their children. Their views of their own future health consequences were less of a focus and seen as way off in the future.

**Theme 4- “Blessing in Disguise”- In reflection, women experiencing GDM identified the condition of pregnancy as an opportunity to take better self-care.**

This theme reflects a form of restitution of the women’s narrative from the chaos and self-blame induced by the condition of pregnancy. A significant portion of the women with GDM expressed that their condition was as P1 described “a blessing in disguise”. As with previously mentioned themes, there was a clear distinction between the experiences of women with GDM and the women with other pregnancy conditions for the “Blessing in Disguise” content. The GDM experience will be covered first.

**GDM group.** The women with GDM viewed their pregnancy condition as an awareness-builder of their future health projections as well as a confidence-booster that they can, in fact,

influence their health outcomes. In addition, some participants viewed their pregnancy condition as a gateway to access mental health support. P2 felt the condition offered her the chance to change her health “It’s a silver lining, right? Like it’s not good to have diabetes, but for me, it was really good, because it got me in check, right?” Another participant described the knowledge she gained on how food choices impact her hormonal response, based on the feedback she received from blood sugar monitoring on food choices:

...the impact, like the knowledge and awareness of how the foods that I eat impact my body and its ability to work properly is definitely still um...I still have that in the back of my mind like I eat this bag of chips, my insulin levels are probably going to be very high so its too much so I think that’s a positive (P8, GDM)

Some women also discussed a sense of mastery with modification of diet and the subsequent improved blood sugar response. Blood sugar monitoring helped to build self-efficacy in dietary choices and the women’s role and ability to change their diet for the better. P6 (GDM) described the feeling of empowerment when blood sugars were in target:

Since being pregnant, and continuing, like after the pregnancy, I realized how manageable it actually was, continued with the diet, and I’ve actually done a lot differently in what I eat now, so I never went back to eating the way I was before... I think it (gestational diabetes) actually made it (my health) better... so I actually think it was a good thing (laughs) if you could say that about gestational diabetes.

P2 also described a sense of confidence with her insulin injections and learned how to adjust her dose to the size of her meal. Feelings of self-efficacy with blood sugar management was also described by P8:

I was controlling it with food, it was an awesome feeling, and made me feel like pretty confident in my ability in eating healthy going forward. So, when I was diagnosed it brought an awareness to my health and that I could control it.

Interestingly, two participants realized that their GDM diagnosis was the catalyst for seeking help for mental health both prenatally and when facing challenges with postpartum mood. P1 explained that she was offered mental health support alongside her diabetes management support immediately after her diagnosis. She reflected that learning of her GDM precipitated her understanding that she needed help with coping in other areas of her life as well:

...with the self-care there was a lot to take in and I wanted to talk to somebody. There were other reasons I wanted to talk to a social worker, but I also wanted to because the diabetes was a little much. I think the diabetes was a gateway for me to open up about a lot of things... so again, as horrible as it was, I definitely had mental health issues that I've been taking care of now and I've been doing much better. So, thank you diabetes (laughs)!"

The GDM experience was also perceived by P1 as the reason she was receptive to go back to get screened for postpartum mood disorder. She felt she wouldn't have gone for help postpartum if she had not initiated a strong relationship with a social worker during pregnancy. This change in engagement in with mental health support, that might otherwise have been avoided, is evidenced by the following quote about P1's mood challenges postpartum:

I'm now in a support group. It's kind of funny because when you go back and you're more open, and it goes back to the gestational diabetes. Like if I didn't start talking to Lana, I feel like I probably wouldn't have gone to the doctor, I wouldn't have been more

open to doctors or to friends and family because I'm a very closed person... So when I talked to the doctor saying I don't feel great and I'm afraid of how I've been feeling...

P10 was the only GDM case who did not relate to the "Blessing in Disguise" theme.

Although she indicated a desire to maintain her lifestyle changes from her pregnancy, she did not see her pregnancy condition as a positive. This could be partly explained by her lack of social support. The women who came to appraise their conditions as a blessing in disguise all seemed to attribute some of their success to their social support networks. P10, however, had little access to social support and this will be discussed more in Theme 5.

**Other pregnancy conditions.** The women without GDM, on the other hand, did not speak about their conditions of pregnancy as a "Blessing in Disguise". They saw their conditions as transient and baring little influence on their future health. P3 (SGA baby) attributed her awareness of her health risk on family history alone and did not feel that her pregnancy played a role in that. She appreciated the postpartum clinic as a reminder of her health risk but did not view the pregnancy as the reason for her health to be a priority:

...I wouldn't say the pregnancy played a role in wanting to be healthy. It would definitely be more on my family history and that sort of thing because I know it is a history, so I know it's a risk for me.

Another participant (P9) described her commitment to health being about becoming a mother, not having a condition of pregnancy. "...and to me the big thing was more so having a daughter not so much having preeclampsia (laughs)". Also, preeclampsia did not serve as an opportunity to access mental health support for P4. She reported having a long history of mental health issues but did not seek help from her prenatal health care team. Perhaps this service was not offered to her. She did not establish relationships with her healthcare team in the same way as a

patient with GDM who would have had many more encounters with their team. “I’m not a very open person, so to go to a counsellor or to go talk about my feelings with someone is not something that I would do.”

The positives of having a risky condition in pregnancy was a strongly discussed topic for women who experienced GDM. They saw their conditions as a gateway to better mental and physical health. Women with other pregnancy conditions, however, saw their conditions as baring little influence on their health and wellness journeys.

### **Theme 5- Risk as Inequitably Distributed- Women’s access to resources either aided or hindered their health journeys in pregnancy and postpartum**

This theme describes how risk does not begin and end with women’s pregnant bodies, but instead comes from the world in which these women live. Facilitators and barriers to self-care for the participants were discussed at length in the interviews. The women’s health situations were influenced by environmental and social contributors as well as the women’s personal and historical contexts. Pregnancy and early postpartum barriers were unique and new challenges and supports with the transition to going back to work were described. Social support, and its influences on ability to meet the challenge of routine health-promoting behaviours was a strong sub-theme from this section of analysis.

**Pregnancy and early postpartum.** During pregnancy, the barriers discussed by participants included income, working conditions, physical environments, physical discomforts and social support. Finances were cited as a barrier to accessing medication, for example P1 (GDM) recalled “for finances, that was hard because of not having any benefits... sure, I had school benefits and it didn’t cover insulin.” A toxic work environment was considered

responsible for one participant's apathy and inability to self-regulate towards health-promoting behaviours:

I think the job was killing me... when I went off work for 3 months and just had that break to clear my head, it became abundantly clear how toxic my job had become, and I was really able to think about my health (P2, GDM).

Health determinants like income and precarious employment existed for these women *prior* to their pregnancy conditions and could have played a role in their development as well as management. They are both examples of how health conditions do not exist in a vacuum. Winter and rurality were also cited as barriers to access to physical activity. P1 described her daily routine, "it was winter and I didn't even want to be outside and when I got home I had no desire, maybe tomorrow." Cultural displacement also posed barriers. One participant referred to her immigration to Canada as the point when her physical activity levels dramatically decreased:

It was eight years ago when we came to Canada. Eight years ago... I was a pretty active person. I was going to like badminton classes 3 times a week, I was going to swimming classes 2 times a week and I was going to skate classes once a week...and I was active all the day and when I came, when I immigrated to Canada, I stopped everything all of a sudden and you know the lifestyle totally changed (P10, GDM).

P10 also described her challenges finding suitable, culturally appropriate health resources. Specifically, she was accustomed to organized sports with a coach for adults in her home country. "There are basketball classes but I'm not sure if for our age, there are any instructors for doing this, so if there were more people teaching you to do some type of sports, that would definitely help." P10 described that her social expectations for sport were not met in Canada. Not surprisingly, she reported that stopped all these activities "all of a sudden" as part of her

immigration experience. Immigration is yet another example of how social context can be a risk to a woman's health.

The women discussed unique challenges related to physical symptoms of pregnancy. For example, nausea and vomiting and gastric reflux influenced some women's desire to eat nutritious foods, "the last thing I felt like doing after going and throwing up all night was going for a run or going to the gym" (P3, SGA baby). P10 described wanting something to sooth her symptoms yet being fearful of the impact on her blood sugars.

I was having um, Coke, or Crush, or this things, but after the day I had to change to diet Coke, which I didn't like the taste but I needed something like sharp...I was sick throughout the night until I go to sleep and because I didn't have like I was, I felt hungry, um, and I wanted to stop my blood sugar to go up, I didn't eat too much. I had reflex of my stomach and I had like uh, what was it, heartburn.

Others discussed the fatigue associated with pregnancy and how this limited their ability to prioritize and enact healthy behaviours, "I was really tired and was really sick in my first trimester...I just...I just slept, and when I woke up I ate what I ate. I didn't think a lot about it" (P2, GDM). Musculoskeletal pain of pregnancy was also cited as a challenge to regular physical movement P3 (SGA baby) recalled some of her struggles "...like sciatic pain and that kind of thing. I think I had every annoying symptom you get when you're pregnant um...so that kind of affected my kind of...uh exercise quite a bit".

The women's personal and historical context was another important influence on health behaviours. Women discussed their personal history with food and their bodies and how this influenced their dietary adjustment journey. For example, one participant referred to her disordered eating history as playing a role in her food intake in pregnancy.

I think I had some food issues growing up. I had some bulimia and uh...so...for me I sort of eat what I want when I want right and... um...I feel like my job was...making me not pay attention as much to my emotional eating (P2, GDM).

P2 described how she adjusted to non-restrictive eating as a means of rejecting her previous eating disorder. Another woman reflected on how she was raised with food in her immediate family and that “junk food” was a normalized experience. Her upbringing around diet was quite different than the way she was being told to eat for her pregnancy condition. She was therefore expected to make drastic changes to food patterns that had been developed since childhood.

I grew up in a household where we ate boxed food and canned food and junk food and that was just normal for us. So growing up I knew it wasn't what it should be but I also knew no different. So, when I made these changes, it was a huge change...(P6, GDM).

Furthermore, P10, who immigrated to Canada in adulthood, described the role certain foods play for her traditionally and how it was not straight-forward to simply limit foods of cultural significance such as rice “It was a very tough experience, especially, um, I realized the rice that I eat, because I am, I am the rice lover”. Food for P10 represented positive feelings about her home country and her identity as an Iranian woman. For various personal reasons, several participants from the GDM group elaborated on feelings of restriction when it came to adjust their diet for their pregnancy condition.

**The burden of restriction.** Many participants with GDM talked at length about their feelings of restriction around food during their pregnancies. P1 misinterpreted nutrition advice about carbohydrates initially and felt that she made herself ill by restricting her intake so significantly. “I remember for a little time period I made myself a little sick because I was so



careful with what I was eating.” P6 described other medical interventions she was required to do in pregnancy and how the food adjustments were one more thing to add:

...so on top of everything else, I was going to have to do *another* injection and I was going to have to worry about *another* thing about eating, even more restricted than I already was... I’m a really, really picky eater. I get texture aversions, I guess it’s the best way to put it. So finding things in the list of things I could eat, I found very restricting”

P10 also talked at length about her feelings of restriction. Her initial response to the question “tell me about gestational diabetes” was simply “stopping me from eating my sugar (laughs)”. She then went on to explain how important her sweet dietary items were for coping.

I had in the mornings, I had morning sickness, so what helped me go through the mornings was my tea with lots of sugar in it...you know for myself, going on a diet was, is the hardest thing in the world. I like to be free to eat anything... (P10, GDM)

P2, on the other hand, did not feel restricted while following gestational diabetes diet advice, “I didn’t really have to change much of my diet to be honest. I just had to limit my carbs and limit the extra snacking...mentally and physically, I felt great.” P11 described feeling less restricted by the “gestational diabetes” diet. “The thing... is uh when I was gestational diabetes and before you know, before this when I go on a diet, I don’t eat carbohydrates, and now I can’t do that. I have to have carbs like with every meal” (P11, GDM).

Some of the facilitators to change behaviour in pregnancy discussed were early leaves from work, accessing compassionate medical supplies and social support. P11 recalled being permitted to take an early leave from her night shift work to focus on the necessary health behaviours for successful GDM management “after 5 months I stopped working and so that kinda helped me though...cause you know I wasn’t up all night eating and you know...” Social

support was specifically mentioned by most participants as a key driver to their health context and will be elaborated on below.

**Postpartum.** The initial postpartum period when the women were on maternity leave was viewed as a great opportunity to focus on personal health and well-being. For example, P2 described her access to both mental health support and physical health resources such as a gym pass:

Since I've left work, I can actually be active on my days off and since I started this medication, I want to be physically active. So you gave me that prescription (YMCA pass) so I go to the gym probably 4, 5 times a week...(P2, GDM)

P11 also described the opportunity to focus on her family while on maternity leave "before I was working, right? So it's different, now I am more relaxed and just concentrated on my kids..."

However, barriers postpartum were also discussed, specifically the barriers of going back to work after maternity leave. The most frequently discussed challenge when women went back to work was lack of time. Time was viewed as limited for food preparation, physical activity, interaction with children, and for personal stress-reduction activities. P9 (Preeclampsia) reflected on time when considering self-care "...just trying to make the time when you know if I missed a couple days of you know not exercising it's hard to find the time right now."

One participant reflected on how she will struggle to manage her night shifts when she restarts work after maternity leave:

I have to have a whole new plan cause I eat during night time and I sleep all day and I will miss probably I will miss my breakfast and lunch and by the time I get up uh I'll have I don't know how much dinner, you know what I mean? And I'll have to really control myself not to eat junk food at night and then bring healthy foods...(P11, GDM)

The facilitators to health in the postpartum period that were discussed included having access to a work-place environment that allows for breaks for regular physical activity, approaching food choices with a non-diet mentality to prevent feelings of restriction, and support at home to allow for women to still do activities for themselves after work or on weekends.

**Social support.** Social support, or lack thereof, was discussed at length by most participants as a major influence on health behaviours both during pregnancy and postpartum. Social support was helpful for GDM management in that women learned from peers online what to eat and exchanged personal experiences. The peer support found online will be elaborated in the next session on communication. Others discussed supports at home to help with groceries and food preparation. For example, P6 (GDM) described her partner creating “homemade chips that actually tasted good”. Many women found just having people in their life to talk to about their condition of pregnancy was helpful for emotional regulation. P8 described her “support team”, “...not just the doctors, but my husband and my mom and uh my aunts too because some of them have diabetes, so I had a really good support team. I think it (social support) plays a huge role”. Many participants felt that social support was a key component of their success with their pregnancy condition management. P6 attributed much of her success with self-management of GDM to the people in her life. “If I didn’t have the support the way I do with my husband and my family, I would not have succeeded the same way”. In the postpartum period, some women found others on maternity leave to spend time with, share pregnancy experiences, and do baby workouts. P3 elaborated on her extensive social circle and how this facilitated day to day health. “I was really lucky that I had about 4 or 5 people that were all off on mat leave at the same time, so we had that network.” She also could drop her baby off at the grandparents’ house when needed and a supportive partner at home.

However, there were also unhelpful social influences such as nagging about food decisions, judgement, and unwanted lay-person health advice. For example, P10 described:

...they (family) just give you advice I didn't want that kind of conversation. Especially because I was pregnant, they wanted to call me and like um, ask you how are you and how is everything with the baby and we overhear you have diabetes, do this do that, why didn't you do this, you should be ashamed of doing this..."

Another participant described her partner's unhelpful influence on her eating "...we were bad for each other when it came to eating, so we would eat out a lot..." (P1, GDM).

Women who were less resourced socially felt the paucity of social resources more acutely in the postpartum period. P10 described the influence of her social network being in a different country:

I need support to taking care of the kids that I have, like right now my mom is here, but she is going back tomorrow, so if I had, and the problem is, I don't consider myself as a social person to find friends easily, and if I have friends, I'm not too likely to ask them to take care of my baby if I want to go to classes. But if I had like more support from family, if I had access to my family easier...

Also, P11 (GDM) described the structure of her relationship to her spouse as a barrier. He lives and works abroad while she manages three children and a night job "he's not here right now... he works in Europe."

The women discussed barriers and facilitators to their ability to enact health-promoting behaviours that often existed before pregnancy and will continue after, with the added challenge of the addition of a child to their lives. The participants' pregnancy and maternity leave conditions presented with different challenges and opportunities for healthy lifestyle actions than

their postpartum, back to work situations. The challenges in pregnancy included juggling work and family demands, physical symptoms of pregnancy and lack of access to culturally appropriate health resources. Postpartum challenges included lack of time and learning new routines with back to work. The women described the importance of social support in depth as underpinning many aspects of their health condition journeys. The next section will move to the women's experiences with risk communication in the health care context and beyond.

**Theme 6- Medicine's Role in Risk- Medicine played a role in communicating, identifying and intervening in risk for the women**

The intention of this study was to focus on long-term risk communication by health care providers, however, when prompted about risk, responses from participants were often focused on immediate risk as well as future risk for chronic disease. For this reason, both short and long-term risk discussions will be presented in this section. Sub-themes of risk communication were organized into three areas: the manner and content of risk discussions, timing of the risk information, and mediums of communication, specifically online.

**Risk Communication/Percentages.** The natural grouping for this sub-theme is to look at the experiences of participants who went to a formal risk communication clinic postpartum separately from the women who got routine prenatal care. As discussed in the methods section, the women who attended a postpartum CVD risk clinic received medical information about their future risk, lifestyle recommendations for prevention, and future screening from primary care. They each completed a detailed risk assessment and health questionnaire. Most of the women in this part of the sample were already engaged in healthy lifestyle behaviours such as not smoking, exercising regularly, and eating nutritious food. They each seemed to take some small tips away from their risk conversation but for the most part the advice was carry on as usual. Many of the

women (3/5) recalled receiving a risk calculation score of “low risk” from the clinic visit. For example, P3 (SGA baby) recalled “I was low risk for um, everything they came across...he was sorta happy with those results, and he said he gets about 50-50 high risk and low risk.”

The women in the low risk category believed they would have felt differently about their health projections and responded with more urgency if they were deemed “high risk”. P3 reported she would have taken the news differently if she had been in the high-risk category, but it was instead the information that did not overly influence her view of her personal health:

Maybe if I had that high risk category, I might be more focused or think of it as more serious...if I was high risk, I would have had a more serious conversation with my family doctor about you know what I could do to mitigate it (P3, SGA baby).

P9 recalled receiving a report in the mail about her future risk calculation but she did not recall the actual content. She tucked it away in case she needed to access it again one day but did not immediately find that it influenced her view of her health. She recalled being told to keep her “diabetes in check”, which is something she was already aware of and “monthly blood pressure monitoring”. P5 (HELLP syndrome) was quite interested in the results of her risk calculation because of her family history “My dad has uh...passed with a heart attack so heart disease is always on the back of my mind...” She also received a low risk score and the advice was to carry on with her current lifestyle “so they gave me a pretty good report that there’s not a major concern with me.” Only one of the five participants who went to the risk clinic recalled receiving a “high risk” score. P6 (GDM) recalled with accuracy what the implications of her health score could mean for her future health:

He told me about metabolic syndrome... it’s a combination of any two cardiovascular diseases, so when you have high blood pressure and you have high cholesterol, which is

what I had, uh, combined they put you at much greater risk for having a stroke or a heart attack.

P6 took the risk information to heart and continued a path she had started in pregnancy to dramatically change her eating and activity levels. She recalled that after her visit to the risk clinic “I had shifted my eating and exercise to the point I didn’t have metabolic syndrome anymore, my cholesterol had normalized” (P6, GDM).

P4 (Preeclampsia) on the other hand, reflected on the use of risk percentages as a communication strategy from her health care team as not helpful and provided false hope. She always seemed to fall into the low number of cases of a negative outcome:

I was having an epidural and there was a 10% chance or 1 in 10 that it was gonna fail and it failed um...it was um...even Pre-eclampsia like 16 percent or 8 percent that fell into that...So it just felt like every time we were given like this might happen. or we can get there, or there’s a small percentage, I always fell into a small percentage.

Although P4 seemed to fall in all the low ends of percentages she was given (10% chance of this...) she reflected that knowing there was a chance of something, even if it was a small chance, is better than not knowing at all.

“It would be worse if someone didn’t tell you, I think I would be more upset I think if someone said oh no its going to be fine and then afterwards be like there was a 10 percent chance so I think its better to know the percentages I just, and the situation can sometimes feel horrible (P4, Preeclampsia).

The women who had usual prenatal care without a formal risk discussion seemed to all wish they understood their future risk and risk mitigation potential better. Only one of five participants in this group mentioned an increased risk of heart disease after gestational diabetes,

whereas all participants mentioned their increased risk of developing diabetes in the future. P1 (GDM) had many unanswered questions about her future health risk:

I guess like coming down to it I wish I asked more...like if I was told more later in life there was a chance I could get diabetes but I wish I asked for some literature so it's something I can learn more about myself...I didn't even bother to ask, and I should've asked... so I think I feel like I am kind of, its very foggy, when it comes to like how, how does the higher chance work. Where were my chances beforehand like before I had gestational diabetes, so...yeah I kinda, I feel like I'm just in the dark with that.

As mentioned previously, P8 demonstrated her agency in her health journey by reading about her future susceptibility to chronic disease online. Although she attended her prenatal clinic as well as a diabetes education center, she reported receiving little to no information on future risk. She instead took information from online to decide that she had little control over GDM prevention:

I haven't been given too much information. I mean from what I've read, um...there's not a whole lot you can do to especially once you've had it the first time it almost a guarantee you'll have it a second time, but that comes from me reading things on the internet. I haven't been told one way or another for having a second child so um...yeah I don't really, going forward, aside from the obvious, you know, eating well and exercising, I don't know if there's any way to prevent it from happening with the next one.

There was clearly a difference in understanding and making sense of future risk between the women who attended a formal risk clinic and those that received usual prenatal care.

**Reassurance.** Reassurance was often discussed by the participants as a positive aspect of health care encounters. They discussed reassurance with respect to the short-term risks associated with their delivery outcomes and the risks associated with future pregnancies. The



women felt scared and unsure about the short-term outcomes of their conditions. They appreciated the comfort provided by HCPs that things were most likely going to be ok. P8 (GDM) recalled:

The clinic was certainly helpful in that they kinda reassured that as long it's controlled, it's not a big deal and they made every effort to keep an eye on his size and reassure me that everything was gonna be okay.

Reassurance from the doctor was also helpful for P1 (GDM) to counteract the fear-inducing advice given by friends:

I remember I asked Dr. M...he was like as long as you're eating properly and you're taking your insulin he's just like you're fine and he was like if your sugars high you just have to take medication but we're gonna monitor it. I remember after I talked to my friend I was like you freaked me out man and she was like okay, first of all don't worry about it (laughs)...You already threw a spark in there, huge fire, (laughs)...don't worry about it. I felt better when Dr. M explained it...

Another participant described after her previous pregnancy loss, she was offered additional tests and more frequent appointments that she felt were not even medically necessary, but instead were for her and for easing her mind that things were progressing normally in her pregnancy. P4 (Preeclampsia) recalled:

It was just for me to know that everything would look great and he would do additional things to help ease my mind to check your like, acetic acid levels and stuff. So he did a couple extra of those so just that way I felt, like it was for me, it wasn't really for anything else, cause this pregnancy was perfect.

Reassurance was also discussed during the postpartum period. Women who were considered “low-risk” for future chronic disease were appreciative of the reassurance that their health had “normalized” postpartum and they could carry on with their usual health-promoting behaviours. P5 described “it was kind of nice just to have reassurance that um...like that I’d recovered since the pregnancy and everything had come back to normal”. Reassurance was also discussed for women who planned to have additional pregnancies. They went to the postpartum risk clinic seeking reassurance that it was safe for them to try again. Reassurance was also brought up with respect to the severity of the pregnancy condition. P9 recalled that the first time with Preeclampsia is usually the most severe and subsequent pregnancy conditions are less severe. She also felt encouraged that there was a prevention plan for future pregnancies:

I think it was more just worry that if I were to have another child, you know if this were to happen again...just that they would start me on the low dose of aspirin...those were basically the big things and just kind of reassuring that the first time around is usually the worst.

Another common discussion point about the way risk was discussed was the presence or lack of judgement and preconceived ideas about patients in clinical encounters.

**Risk from Medicine- Judgments and Assumptions.** Many women spoke about risks to their self confidence and sense of agency that came directly from their healthcare experiences. Some participants described preconceived judgements from health care providers about their current lifestyle and/or home circumstances. For example, one participant was told shortly after her initial elevated screen for gestational diabetes that she should “lay off the chocolate” with little knowledge or assessment of this participant’s current eating behaviour. These judgements

came up for another participant about her body size. P2 described her experience of being in labour and a nurse giving advice that she should lose her baby weight as soon as possible:

It was funny cause I hadn't gained, I had lost weight during my pregnancy like when the baby came out I was lighter than I was before (laughs) I got pregnant but she was like you need to lose this baby weight...little did she know I was fat before I got pregnant what is she talking about 'this baby weight' (P2, GDM).

Another experience of judgment occurred from the neonatal intensive care unit (NICU). Some health care staff seemed to act as gate keepers to the locked unit. One participant described her desire to be there as often as possible and spend time with her baby, yet she felt this sense that she kept having to "prove" her worthiness as a mother and that her life choices were not the cause of her small baby. "They're trying to read your situation and they're trying to figure out why you know, what lead you to have a premature child so you feel a little judged um...and... you kinda wanna say there's really nothing I did!" (P5, HELLP)

Others described their experiences of a lack of judgement from HCPs, which helped to counteract some of their own self-blame about their conditions. This experience seemed to occur predominantly in the GDM group. Women spoke about the plain, matter-of-fact language some HCPs used to describe their condition, and how this helped to shift some of the self-blame they were experiencing. P1 (GDM) recalled "I thought it was something I had done for getting the diagnosis so I definitely thought it was my fault, uh... but thank god the doctor...they explained how some women don't have it but unfortunately, you have it". Some HCPs were even more explicit in their approach that their patients did not do anything wrong or cause their condition. This was particularly evident for P8 (GDM) when she was about to initiate insulin. She was given frank direction from her health care team that her treatment plan was not her fault:

...there was still a part of me that felt like I should have done more, like what's wrong with me that I couldn't control this. It's a small part but it's there nagging at you, so when the doctor was very adamant, this is not your fault, like you've done everything you can to make it better, it was a huge relief actually, it's nice to hear it from a medical professional. You know. My husband can say it all day long but until I hear it from someone who specializes in... in diabetes specifically.

P8 elaborated on her judgement-free medical encounters in her pregnancy with respect to her weight as well. She went into the pregnancy expecting that weight would be a focus for HCPs and she expected assumptions to be made based on her age and weight. She was pleased that this expectation was not met at both her prenatal and diabetes clinic experiences.

You kinda prepare yourself for um it (weight) being a bigger deal to the doctors than, not a bigger deal that's not the right word um them making a point of bringing it up and them saying you really need to do these things and you really need to do that... it was never like wagging a finger at you like you should be ashamed of yourself... (P8, GDM)

P6 also described her future risk discussion as judgment-free, and this was important to the rapport-building and engagement in that encounter where lifestyle health behaviour was discussed in depth. "He can give you all that information and change things that you're doing without making you feel like he doesn't judge you." The participants also reflected on the degree to which short-term risk discussions and treatment plans were collaborative verses HCP-driven.

**Tension between medical and lay perceptions of risk.** Several participants discussed their lack of personal agency in treatment decisions to induce their labours early. Participants reported feeling unsure about this treatment decision and the short-term risk to baby for this

procedure. Almost all (ten out of eleven) women in the sample discussed early induction as part of their treatment plan. Many participants described this decision, including the pros and cons to baby's health, on the part of their health care team being inadequately explained. Women had a strong negative perception of induction and felt strongly about 'natural' deliveries.

I was interested in hearing...whether I could just carry the baby to term because the hypertension was...(sighs) well-controlled and there wasn't any signs that it was progressing. I was wondering that time whether I could um...just wait until the baby wanted to come out and not be induced (P7, Gestational HTN).

P3 (SGA Baby) felt similarly and did not understand why she needed to have the baby ahead of schedule "...I figured well its only like 2 weeks so why wouldn't we wait until like 40 weeks?" Another participant questioned the induction decision before the procedure and then even more when the baby was delivered. The main risk in GDM that she recalled being communicated to her was a large for gestational age baby. So, when her baby was born on the smaller side, she questioned the legitimacy of the treatment decision and worried about the risks to his well-being.

...I had an induction before him, and the reason was that... mothers with diabetes have big babies, so that it was induced so that the baby doesn't grow big. He was smaller even then...like three kilograms... so that's the part that I was shocked... I risk his life, his well-being not his life...Anyways, he was born two weeks earlier, maybe he could be, maybe he could be better, if he was coming by his own you know, right instead of being induced, that I don't know...He was smaller than anything I ever seen, any babies that I ever seen... P10, GDM

Another treatment decision that left P10 concerned about baby's risks was the introduction of insulin. Although P10 was told that there was no risk to baby in giving insulin, she did not feel confident in this reassurance. "I had to inject insulin...which like I was stressed because I thought, all that I knew was that doesn't have any effects on the baby, you know in the bottom of my heart, I was not completely sure."

Many women attempted to enact agency in their pregnancy care by taking part in the clinical decision-making process. However, these women felt excluded in their own care. They desired a dialogue for short-term risk conversations as opposed to one-way information-provision. Women described being left with many questions that were unanswered. They were then more likely to find other resources and supports to answer these questions, a prospect that carried its own risks. Alternative information-seeking will be elaborated on in the next theme on the role of online support. One participant (P1, GDM) described the fear that came up when she considered the risk of induction. She did not feel invited or given the opportunity to ask questions:

They just said yup so your babies this size, so he's very big, um, just make sure you're careful because you don't want, and it's like he starts spitting out medical terms... I was really scared...I was trying to stay calm but I was just thinking to myself like oh my god what's gonna happen?

In this interaction, the medical professional took on the role of knower, using inaccessible medical terms, while the woman converted to the 'not knower'. Participants reflected on a longing for a two-way conversation and the space to reflect on the information given before decisions were made. P7 (Gestational HTN) described how she did not receive the time she

needed to formulate questions to ask the HCP. This was particularly apparent during times of scary decisions such as induction:

If there was more of um, if I had more opportunities, if someone had, someone had made the opportunity like someone to come with some follow-up with how are you dealing? How are you doing with everything, do you have any questions, would have allowed me to ask those questions.

Furthermore, women enacted agency by using their intuition as a guide during the early stages of diagnosis. Some participants sensed something was wrong before their medical team had diagnosed their condition(s). They reflected on the desire to be taken seriously when something did not feel right and to have seamless access to their prenatal team for assessment. There was also the wish for their intuition to be validated by HCPs. P4 (Preeclampsia) wished she was empowered to trust her instincts “I was mostly thinking its education and knowing... when to really listen to yourself and if like you feel like there’s something more, just to be able to have the reassurance or the help that you need...” P7 also reflected on the power of trusting her internal experience “I think during my next pregnancy I’ll be more aware of any, how I’m feeling, and follow up on that and not question it.” Not listening or respecting women’s intuition represents another example of risk from healthcare itself. Another way the women asserted their agency was by seeking information through online searches.

**Risks and benefits of online.** Many participants recalled searching online to learn about their pregnancy conditions. This occurred when women did not receive adequate information from their health care teams, but also because they sought alternate views from peer discussions. This search for potential risks associated with pregnancy began even before diagnosis for some participants; this will be discussed in the preparation sub-theme of this section.

One of the topics that participants used online searches to understand better included the treatment implications of their pregnancy conditions. P3 (SGA baby) was told that the treatment was early induction but did not get information on the process of getting labour started. She was interested in the specific procedures used for induction but found this information was not readily available when she was told she would be induced early. She wished she had thought of questions to ask about the process but found she was too overwhelmed when she was with her health care provider:

The part of communication that I didn't feel like I got enough on was what the process of actually getting the labour started was gonna be... after my, appointment where they decided to deliver him early, I kind of uh...ended up like googling a lot to try and figure out what that actually meant.

Other participants tried to make sense of their conditions by searching online. P4 described googling her condition (preeclampsia) with her family members because she had never heard of it prior to her diagnosis. She found the online search only made her more anxious:

I remember reading it online before I went to the hospital and everyone was like what's this pre-eclampsia thing and I was like oh my god no, no, like, calm down guys, we're getting too into Google, like we're, we're gonna make, we're gonna make our minds upset for things that aren't even gonna happen.

P5 also recalled using online information to make sense of her diagnosis, which was not yet clear in hospital. Her partner and her were attempting to make sense of preeclampsia and HELLP (the two possible conditions doctors were trying to rule out), because her friends and family were asking her "what is HELLP?".



Some participants discussed the risks of lay person online searches of their conditions and intentionally avoided this medium of information. One participant described trying to make sense of lab results that she had access to online before discussing with her health care team. She was left with more answers and confusion:

I looked at the results, because they posted the results online, and did not understand it, and I was like okay, it makes no sense to me, because for my next appointment I was coming here even leading up to it I wasn't sure if I had it or I didn't (P1, GDM).

After this experience, P1 opted out of Google searches all together on the advice of her health care team, as she felt that the information was often too scary and not adequately nuanced without a HCP available to answer questions and put the information into context:

There's people who read up a diagnosis on the computer and its like they can take it way out of context or its just like it freaks them out, because like okay, what's the percentage on this? I'd rather just hear it from a doctor or like someone who knows what their talking about, I'd rather just hear it from them (P1, GDM).

P3 also was concerned about exacerbating anxiety from online searches:

You go home from an appointment and you have questions, your natural tendency, especially these days is to google it and from googling it, everybody knows that basically if you google headache you have a brain tumor and you're dying right like its always worst case scenario... and I think maybe that makes people more nervous and have more anxiety about it, if they're getting more negative than they do positives (P3, SGA Baby).

P4 also mentioned googling and felt that online can be dangerous in bringing up more anxiety and fear instead of settling it:

I killed my child like six times (laughs) googling things and I had a newborn right, so something would happen and I'd google it and she'd be on her death bed is what google was telling me, when really she was just fine...(P4, Preeclampsia)

Two participants, however, discussed how they navigated the internet and sifted through the useful from the less useful and potentially harmful, material. Many women found online searches quite helpful and they were able to discern what information was helpful and what was not. They used the internet to fill in gaps in knowledge as they came up and they used the internet to prepare for possible issues that could come up in the pregnancy. As P8 (GDM) recalled "I mean I didn't really have too many questions about it. That's the beauty of the internet, it answers questions as they come you know...".

P8 also discussed using the internet to make sense of her future risk. She reported not receiving information from her health care team on future risk postpartum, so she used the internet to understand her future risk for herself as well as future pregnancies:

I mean from what I've read um...there's not a whole lot you can do to especially once you've had it the first time it almost a guarantee you'll have it a second time, but that comes from me reading things on the internet...I don't know if there's any way to prevent it from happening with the next one (P8, GDM).

P4 also found out about her future disease from online prior to her formal risk assessment clinic. "I was home on sick leave and the internet is so easy to access. It was a lot of reading about, and that's how I found out about it... their Facebook page had all the information about heart disease."

**Peer support online.** Peer support online helped women navigate risk and provided something that health care providers could not offer. As P11 described, she chose online

searches for an intimate understanding of others' experiences "...just about gestational diabetes and the experience of mothers, you know, what did they do, and stuff like that, how did they feel..." Many participants sought advice and support through other women experiencing a similar pregnancy condition online. This was particularly true for women with GDM. One participant said her reading of others' experiences shaped her approach to her GDM management when her health care teams were providing mixed, unclear messages. She was uncertain as to if she should just expect insulin to do all the "work" or actively attempt to adjust diet to improve blood sugar control:

I tried to be open-minded... cause there was a lot of people who would say "just eat what you want to eat and deal with the gestational diabetes through the insulin" and then there is the other train of thought which is try to deal with it, you know, the gestational diabetes through diet and exercise and so you kinda have to make your own decision in your own mind and that's where the internet comes in handy. It allows you to do that (P8, GDM).

The women were able to read about others' experiences without taking it all as truth. They took the information that was helpful and left behind the other less useful content. As P8 described:

Medical articles from like WebMD or like the Mayo clinic has a couple of articles or some information on it but it's all pretty basic though, that's why people's experiences are kinda nice, it gives you more of in-depth, personalized experience? (P8, GDM)

Furthermore, one participant was able to find an important peer support resource through her online searches. The internet served as an opportunity to debrief and get answers about her preeclampsia after she experienced her pregnancy loss. P4 reported she was more comfortable with getting help through peer support instead of one-on-one counselling. P4 expressed a wish that she had more access to support groups with peers who had similar pregnancy experiences.

She found support through online searches but wished this was more available in-person. She discovered a local annual walk for people who have been impacted by preeclampsia:

After everything that had happened, we knew nothing about Preeclampsia, so it was literally like after it all happened I was home on sick leave and the internet is so easy to access...I ended up finding um...the promise walk in Kingston (P4, Preeclampsia).

Timing of risk information was another commonly discussed topic that will be presented next.

**Preparation/ timing.** Many participants wished they had received information about the potential risks and symptoms of pregnancy conditions prior to their diagnoses in order to be better prepared. Some women did not even know certain conditions existed until they were diagnosed. P1 (GDM) wished she would have been told more about potential conditions of pregnancy so she could have been more equipped to face it when she was diagnosed:

I didn't know it existed till uh my doctor said okay we're gonna have to go for a test because of this, I'm like oh okay, but like, I think, I think if I knew it even before I got pregnant I feel like the blow would have lessened.

P2 also noted that her care lacked early recognition and subsequent screening of her as "high risk" for GDM. She felt she would have reacted sooner and perhaps adjusted lifestyle sooner if someone had been more up front with her about her risk "you know had they screened me, I would have said yeah, I'm high risk, so maybe I would have gotten the education, maybe I would have thought more about it." One participant was proactive and did her own research on potential risks prior to her diagnosis because she described herself as an "older, overweight" woman. She found this early knowledge was a helpful means of preparing herself for the possibility of having a condition like GDM. She did not receive this information from her health care team early. "I did a bit of research on it before I was even was diagnosed" (P8, GDM). In

addition, P4 wished she was aware of some of the warning signs of preeclampsia before it was too late.

...if there was someone who just kind of told me when to be concerned or when to say so, I could have set up my first doctors appointment...I could have said well no, I have high blood pressure and high protein in my urine, this is not...this is not just a bladder infection.

On the other hand, P9 received information from the diabetes clinic early (related to her pre-existing Type 1 Diabetes) on things to watch out for as her pregnancy progressed. She was told it was typical for her blood sugars to go up later in the pregnancy. When hers went down instead and hypoglycemia was harder to treat, she was able to be proactive with her care and get medical attention right away:

With diabetes I was always told sort of after 6 months you could expect to really be fighting with your insulin to know and always increasing it because it would get harder to control your sugars, and I always had a decent control with my sugars, but in this particular week I was finding that I was having low blood sugars and it was so far different from what my care team had told me to expect (P9, Preeclampsia).

Preparation also came up for future risk discussions postpartum. P1, who did not get access to a formal risk assessment postpartum, expressed a wish for more opportunity to discuss her future risk. She was left with many questions about her pregnancy condition and what were the future implications. “There’s still a lot I don’t know about diabetes so it’s just kinda I think its more of not knowing as much as I thought I knew is kinda terrifying...” (P1, GDM).

However, participants had mixed views of when future risk discussions were best to be presented. There were many opportunities in the women’s pregnancy and postpartum journey

where future risk could be addressed. P7 (Gestational HTN) thought that layering the information at multiple appointments would have allowed for the opportunity to reflect and think of additional questions for future conversations. She thought an initial discussion at discharge would have been helpful:

I guess that's a good opportunity to ask, um to say do you have any questions about yourself and your healthcare and do you understand your diagnosis, um, here's what a follow-up is actually going to look like for you (P7, Gestational HTN).

The women discussed the benefits of these risk conversations at diagnosis, at discharge from the hospital after delivery, at the 6-week check, and again at 6 months to a year postpartum. P4 thought after her pregnancy loss, one year postpartum would have been better timing for her to hear about future risk information. She was not ready to hear it at 6 months postpartum but felt a year later she was in a better place to take in the information:

I think maybe a year-ish would be good assuming you've gone through the issue, you've had the follow-up and a year later you're usually a little more healed, you're starting to kinda come around and it might be good time to be like okay here's some more information for you (P4, Preeclampsia).

Another participant discussed her 6-week check that was mainly just a check on her baby, who had some complications, and she didn't receive much attention at all. She would have liked the opportunity to discuss future risk and debrief on her pregnancy experience at that appointment. In describing that 6-week check appointment, P7 reflected "I wasn't a priority".

When not to discuss future risk was also addressed. P2 recalled how a labour and delivery nurse repeatedly mentioned her future risks associated with her pregnancy condition and body

size while she was in labour. She also noticed that the health care provider seemed to wait until she was alone, and her partner was out of the room before having these discussions.

...she kept bringing up my diabetes up in a really bizarre manner. She would wait for my husband to leave the room and then she would have this private conversation with me about my increased risk of diabetes now, but she talked to me like I was dying of cancer... (P2, GDM)

There seemed to be consensus among the women that talking about future risk at more than one encounter would be helpful, however they did not seem as sure that their general practitioners could effectively discuss this topic.

**Lack of confidence in primary care, non-specialists.** Some participants reported a lack of confidence in the knowledge and prioritization of pregnancy conditions and the link to future risk by their primary health care teams. P4 compared preeclampsia to diabetes and felt that diabetes is something that people understand much better and it influences care whereas preeclampsia is relatively unknown. When reflecting on the implications of her knowledge of the link of preeclampsia to CVD:

...it's you know if you were diabetic and go somewhere and say oh like you know I'm a diabetic, people are like oh okay, or um, you know if you had a heart attack in the past, its like oh okay its kinda taken as oh okay this is something that's happened, whereas yeah, whereas I feel like pre-eclampsia's not really, it's something that, I don't know, not really recognized as something that could be an underlying issue or something that could be causing, like if I was to be having heart problems and I was to go in and say oh I had pre-eclampsia when I was 20 would they have been like cool why are you telling me this?

P4 also talked about transitions of care and how she is now reflecting more on her heart disease risk but doesn't know where to access support. She felt that her pregnancies are done so now it is up to primary care to manage her care, but she lacks trust in their knowledge and ability to help:

I don't really feel confident in (her GP) I guess a little bit. I'm still a little bit unsure and then you know with the doctor said the stuff you know that's over because that's pregnancy, I'm not pregnant, I can't really reach out, I don't feel like there's somewhere for me to reach out in that area because its not to deal with how I am now.

Furthermore, P9 wanted specific questions addressed by her family doctor but didn't get the detail that she was looking for until she went back to the specialist clinic:

Yeah she (GP) said I can kinda answer general questions for you and it was stuff like playing Dr. Google I can kind gather on my own...I think this is maybe more of a hospital to GP issue than any issue with that program, but just like maybe more if my family doctor had a little more understanding, for the follow-up, it just seemed like I had to fill in the gaps for her (P9, Preeclampsia).

Unfortunately, P9 also discussed that her family doctor was not even aware of the specialist postpartum risk clinic. "she didn't know a great deal, so I said they said I would be getting a call about this program and she didn't know what that was." When referring to the postpartum clinic and learning about ASA for prevention of hypertension in future pregnancies, P7 (Gestational HTN) reported she did not receive prevention information from her primary care provider. She even booked a family planning session with her primary care provider and there was no knowledge of prevention of future conditions at that appointment:

I wouldn't have known that (ASA for prevention), no one discussed that with me and if I had a follow- up with my own doctor and was planning on another pregnancy I would not



know that or not know my risk...not knowing my risks for having another baby or having another baby what the risk of having it again would be...(P7, Gestational HTN)

**Participant Communication Tips.** The women shared many pieces of advice regarding communication about risk in the short and long-term, and these tips will be presented in the following table.

Table 1

*Advice for Improving Communication about Risk from Participants.*

Advice	Participant	Supporting Quote
HCPs share a small number of reputable online sites.	P4	“...like if there was actual good sites they could refer to or go to I guess gives a good solid you know, these are the symptoms, then seek help. There’s too much out there...”
Detailed checklist prior to procedures like induction and what the procedure is going to look like.	P3	“...we’re just gonna do a Foley catheter and we’re just gonna take them out next week... and I was like I don’t even know what this means maybe just something from the actual physicians themselves that better explains the process as opposed to okay were gonna do a c-section on this day see ya...”
Roadmap of the bigger picture of the prenatal journey.	P7	“...more education on how the whole system works... it’s just not something that’s immediately known to people unless, you only know how you have a baby in the health care system after you’ve had the baby”
Prepare patients for what they might face at home.	P1	“...family and friends just acting like they have more knowledge than me...so I wish the doctors would have said you’re gonna have people acting like they know this but if you have a question just call us.”
Avoid assumptions about a patient’s knowledge. More information is better than less.	P2	“...I’m a nurse and every time I saw a new health practitioner...I had to go through the whole you’re a nurse so...they assume I know everything, and the fact is I know nothing about being pregnant with kids, nothing. I do not work with children...”
Ask “how in-depth do you want the information?”, recognize a person’s life circumstances.	P2	“my mum had passed away 2 weeks before I got diagnosed so when I went to the DEC clinic... she said how in depth how do you want your education? I said I’m not thinking straight right now, so just give me the bare minimum that I need”
Offer “wrap-around” care postpartum for women who are low <i>and</i> high risk for future chronic disease.	P6	“...I think having some postnatal support systems in place. Once you’re done with your pregnancy you go back to your doctor and check your sugars... so that’s it, those support systems in primary care would be beneficial...checking on your diet, on your activity level a little more...”
Avoid generic letters about lifestyle, provide patient-specific advice:	P9	“I think the only thing that threw me off in the report was the wording about exercise and weight, like what do you mean I need to work out more than 5 days a week?”

This section described the women's positive and negative experiences with their health care teams on communication and intervention on risks associated with their pregnancy conditions. They described many quality interactions that were influenced by non-judgement and reassurance from health care workers, but at times, such as during treatment decision-making, communication breakdowns and lack of patient-centered care occurred. The women sought out information and support that was not readily available from their HCPs via various online platforms. They provided accounts of specific actions HCPs can take to make communication more helpful for women who experience risky pregnancies.

### **Discussion**

This paper's findings contribute to the literature on the pregnancy link to future chronic disease by offering an in-depth exploration of women's perceptions of their pregnancy conditions and views on risk. It also explored health care providers' role in communicating, identifying and intervening on risk. The aims of this study were two-fold, to illuminate the pregnancy illness and risk perceptions of women, while situating their views in the contexts and structural conditions of their lives, and to explore women's meaning-making from experiences with risk communication in medicine.

The present study's findings expand on qualitative research that highlights the voices of women who experienced pregnancy conditions, with a focus on the Canadian health care context. The findings expand on the GDM experience and compare to other conditions of pregnancy that are risk factors for CVD. Aside from preliminary work, including a study by Traylor, Chandrasekaran, Limaye, Srinivas and Durnwald (2016) on women's views of risk following hypertensive pregnancies, most qualitative work to date has focused on the GDM experience. To date, we are aware of one study by Eades, France and Evans (2018), based on a

Scottish sample, that explored GDM illness perceptions using the CSM as a health theory framework. The present study shared findings with the Eades et al. (2018) study, including perceptions of minimal consequences to mothers and short illness timelines. The findings expanded on previous qualitative work on health experiences and meaning making of GDM pregnancies such as work by Evans and O'Brien (2005) and Parsons et al. (2018). The present study had commonalities with these papers including disorientation and distress, but in contrast, it illuminated participants' positive and transformative experiences with their pregnancy conditions that led to feelings of hope for the future. Furthermore, the Parsons et al. (2018) study, based in England, found major dissatisfaction with care, which was not apparent in the present study.

This study's findings also expanded on limited previous work, including a recent focus group study in a Norwegian health center by Sandsaeter, Horn, Rich-Edwards and Haugdahl (2019), on women's views of risk communication in health care. This study shared similar findings with Sandsaeter et al. (2019), including the desire for more information about future risk, as well as the need for a debrief after the trauma and shock associated with sudden conditions. The open-ended nature of the present study allowed for conversations about risk communication to move beyond risk knowledge to discussions about the manner and mediums in which risk information is discussed. A novel finding included the illumination of women's information and support-seeking online.

To summarize the analysis section, prominent themes included emotional and physical pregnancy experiences, influences on health self-image, causal attributions with a pronounced collective narrative of self blame, and views of condition consequences focused on "baby first". Positive accounts of women's agency in prioritizing and accessing health supports were also

described but balanced by the structural and immediate challenges to health-promoting living both before, during and after pregnancy. Finally, women also discussed their conceptualizations of risk and the perceived strengths and limitations to risk experiences with their health care teams. These themes will be discussed in further detail below in turn relative to extant literature and potential implications for practice.

**Emotional experiences.** Many participants with non-GDM conditions discussed feelings of loss of control and seemed to lack a sense of ownership over their health conditions. They described a lack of collaboration with their health care team and instead saw themselves as simply passive recipients of health care. The emotions discussed in the present study has similarities to other qualitative research on high risk pregnancies. Evans and O'Brien (2005) explored at-risk pregnancies and emotional outcomes included shock, powerless, vulnerability, and fear. In addition, Roberts, Davis and Homer (2017), in one of the few published explorations of gestational hypertension and preeclampsia experiences, described participants' feelings of surprise and fear. The women had little time during their prenatal experience to process the implications of their conditions and described this process occurring well after their deliveries.

Women with GDM, on the other hand, had more time with their condition in pregnancy to make sense of it and develop a sense of personal control. They felt it was their responsibility alone to self-manage many aspects of their conditions. The pregnancy experiences of women with GDM has been discussed extensively in the literature. An interpretive review of 19 studies from around the world on GDM experiences found that women experienced shock and lack of preparation with initial diagnosis and in contrast to the present study, the participants' negative feelings seemed to persist throughout the pregnancy (Devsam, Bogossian & Peacock, 2013).

Feelings of loss (of spontaneity), vulnerability, and despair for the future were common. Day to day struggles to manage GDM were described as stressful and overwhelming. Also, feelings of loss of control and inability to manage blood sugar outcomes were cited (Devsam, Bogossian & Peacock, 2013).

**Implications for practice.** These emotional accounts underscore the need for an opportunity for women, particularly those who deliver shortly after diagnosis of a condition in pregnancy, to debrief about their experiences and subsequent implications of their conditions. An opportunity to debrief postpartum, at a time of their choosing, about one's pregnancy condition could facilitate the process of moving on and considering the future health implications of the conditions. It could be argued that for many women, risky pregnancies are traumatic, and healing needs to occur before there can be room to contemplate the condition's implications on future health. Evidence exists that there is a high prevalence of PTSD symptoms following high risk pregnancy complications (Forray, Mayes, Magriples & Epperson, 2009). Perceptions of pregnancy health conditions that might influence the emotional experience include the presence or lack of physical symptoms.

**Symptom identity.** Many women with pregnancy conditions did not experience any physical symptoms of their illness. The women understood their illnesses to be indicators of a problem as described by their medical team, whereas somatic experiences were rarely discussed. For example, women were told that their blood pressures were elevated, their blood work showed low platelets, their blood sugars were above cut off points and their belly measurements were not matched to their age of gestation. Few of these indicators were confirmed with embodied experiences for the women.

According to the Common-Sense Model (CSM), people often define their illnesses through their symptoms. As explained by Cameron and Moss (2010), a common-cold is an example of this. People experience symptoms like runny nose, recall how these symptoms have been managed in the past, and if rest and warm fluids has worked before, will follow this protocol. If after a while symptoms do not resolve, they will adjust their mental model to perhaps a sinus infection and reappraise an appropriate course of action. Physical symptoms of illness are an example of a concrete representation, as described by Leventhal (1990). Abstract mental models, on the other hand, include beliefs about cause, consequence, and timeline of the illness. Concrete verses abstract illness representations, and how these perceptions work together to influence health behaviours and coping, have been considered extensively in the health psychology literature. Concrete perceptions are often developed based on somatic information from previous experiences with illness. It is posited that people consider abstract information, such as the indicators given from a health care provider (HCP), to link symptoms with labels or diagnoses (Hagger & Orbell, 2003). The asymptomatic nature of pregnancy conditions requires reliance on abstract representations of illness to make sense of their experience. Without concrete data, one's emotional response could be blunted, which could reduce the desire to be on board with medical advice about the condition (Cameron & Moss, 2010).

In the instance where no symptoms are present, some people will search for symptoms to help make sense of their condition. For example, in early work on hypertension, a largely asymptomatic condition, study participants were aware that this condition does not have symptoms, yet most felt that they can tell when their blood pressure is high or low (Baumann & Leventhal, 1985). People were also less likely to continue taking antihypertensive medication if they believed they continued to have symptoms despite taking medication. This indicates that

people who have been told to follow a treatment plan that does not resolve their “symptoms”, must have confidence that the treatment is helping their abstract indicators of illness (blood pressure numbers). Searching for symptoms came up in the present study, where a few participants discussed symptoms that medically were not related to their conditions, yet this seemed to help with processing their conditions. Moreover, symptoms that could be related to a condition like GDM in pregnancy such as fatigue or excessive urination might be masked by the same common symptoms of pregnancy.

**Implications for practice.** Health Care Providers (HCPs) could ask women about their perceived symptoms of illness or lack thereof to better understand how women are making sense of their conditions. What is their somatic experience? Do they feel their symptoms are resolved when they take their insulin? Or does it not change anything? Do they have less confidence in the decision to induce labour because they do not experience symptoms that support the notion that there is a problem with the pregnancy? An explicit discussion of these perceived symptoms might help patients with processing their conditions and provide an opportunity to align patient beliefs with treatment plans. The next prominent health condition perception that will be discussed is related to the women’s views of the cause of their conditions and ensuing self-blame.

**Self-blame and personal responsibility.** The women’s perceptions of who or what was responsible for their conditions influenced their sense of agency over prevention practices for future health risk. Many women with GDM viewed the cause of their pregnancy conditions as strongly related to their personal health behaviours. Taking on the cause of their illnesses personally led to many women feeling self-blame. Self-blame is a shared experience cited in the qualitative literature on GDM pregnancies. For example, a recent qualitative study found that



self-blame was a common emotion amongst an ethnically diverse sample of women with GDM (Parsons et al., 2018). Prior research suggests that negative, self-focused emotions like self-blame is associated with lower confidence in one's abilities (Neff, 2003).

An important counter approach to self-blame is self-compassion. Self-compassion has been studied extensively in Eastern Buddhist scholarship and has been defined in Western literature as “self-kindness verses self-judgement, a sense of common humanity verses isolation, and mindfulness verses overidentification” (Neff, 2003). The concept of self-compassion and its role in health outcomes has been a recent topic of interest in the literature. A study with patients with Type 1 and Type 2 Diabetes found that higher self-compassion moderated the impact of diabetes distress on health indicators such as glycated hemoglobin (A1C), a measure of blood sugar control (Friis, Johnson, Cutfield & Consedine, 2015). Self-compassion has been positively correlated with health-promoting behaviours such as healthy eating, activity, sleep and stress-management (Sirois, Kitner & Hirsch, 2015). Furthermore, a recent meta-analysis of randomized control trials found that self-compassion interventions improved a range of psychosocial outcomes including depression, stress and eating behaviour (Ferrari et al., 2019). How to engage women with pregnancy conditions, specifically GDM, to embody self-compassion warrants further research.

Much of the discussion about the cause of conditions was simplified by the women (with GDM specifically) to individual personal responsibility. Furthermore, Lupton (1999) describes that when risk is viewed as a personal choice because individuals have been made aware of it, then they become responsible for the risk. If they do not mitigate the risk, then the blame falls on them. An example of taking on responsibility for risk is the discourse on the “good fatty”. People living in larger bodies are viewed as morally just if they are physically active (Bias,

2014). Despite lifestyle playing a major role in many preventable illnesses globally, it is important to make note that individuals cannot be held entirely responsible. Society's role in access to healthcare, sanitation, urban planning and occupational health are just a few examples of how individuals cannot take on the full blame of their health issues (Resnik, 2007). Individual verses societal responsibility for health outcomes has been discussed elsewhere. A Norwegian sample of citizens agreed that both individuals and societies are responsible for lifestyle-related illnesses (Traina, Martinussen, & Feiring, 2019). Yet the narrative remains, particularly in the medical field, that health issues can be simplified to personal accountability.

Furthermore, specific to pregnancy, women are often blamed in medical discourse and society as a whole for decisions such as age of conception, while men's role is not considered. Just as average maternal age is increasing, so too is paternal age. Research suggests that advanced paternal age influences fertility, fetal risk of birth defects, some cancers, and schizophrenia (Bray, Gunnell & Smith, 2006).

Diabetes stigma is one example of how societies view health responsibility. A qualitative literature review found that diabetes is often viewed as self-inflicting and primarily caused by greediness with food consumption (Abdoli, Doosti Irani, Hardy & Funnell, 2018). The study found that diabetes was also viewed as a condition caused by laziness. This stigma was observed in samples across the globe including Iran, Australia and Taiwan (Abdoli et al., 2018). Likely part of the reason self-blame is a common experience for women with GDM is because of the underlying, and often invisible, stigma associated with diabetes as a disease in many societies.

**Implications for practice.** The strong sense of personal responsibility and self-blame related to GDM influenced some women's ability to self-manage their condition. Self-blame and excessive rumination can get in the way of being future-oriented and mobilizing self-care

behaviours (Biber & Ellis, 1981). For example, one participant was hesitant about insulin initiation because she was heavily invested in her personal responsibility, in the form of diet adjustment, for her blood sugar control. As discussed by women in the present study, sharing with patients that these conditions are not their fault, promoting self-compassion and offering mental health support to process these feelings might support women to self-manage their health during pregnancy and after. Furthermore, explicit discussion early on the placenta's adaptive role in insulin sensitivity might help to alleviate the feelings of self-blame when exogenous insulin is warranted. Women recalled learning about their conditions in terms of their pathology and "indicators" but did not learn about the adaptive and protective aspects to their pregnancy physiology. The pregnant body is miraculously undergoing extreme changes not experienced by any other human process. For example, the pregnant body is continuously adapting its maternal cardiac output and oxygenation to the competing needs of fetal growth and its own cardiac output (Dennis & Castro, 2014). Increased blood pressure in pregnancy can be viewed as an adaptive feature for placental vascularization. Also, maternal insulin secretion increases in early pregnancy and insulin sensitivity adaptations occur in order to grow needed adipose tissue (Barbour et al., 2007). These adaptations are natural and unique to pregnant bodies. When these processes become exaggerated in certain pregnancies, insulin resistance does not match insulin production or blood pressures rise too high, they become maladaptive. Often medicine focuses on the pathology and risk of women's bodies while not acknowledging nor discussing with patients the beauty and strengths associated with these processes. These natural adaptations could be discussed with patients to reduce the "othering" that occurs with pregnancy conditions and as a means of encouraging self-compassion. The common experience of self-blame for women with pregnancy conditions could also be related to how the condition's cause and

management is communicated by health care teams and wider society. Reflection by HCPs regarding the many influences on a woman's health (such as income disparities, the food environment, intimate partner violence, and trauma) is warranted when working with women with lifestyle-related pregnancy conditions. Women's perceptions of consequences of their conditions will be presented next.

**Baby first.** The mothers in the present study focused on their babies' well-being as paramount when they considered many aspects of their pregnancy conditions. Possible consequences to the mothers themselves seemed to have much less impact on their prenatal illness perceptions. Many mothers with GDM in the present study focused on baby's size because of their pregnancy condition. One mother used imagery of her baby's skin stretching to process what might happen in her pregnancy. Women mentally created concrete representations of the illness impact for baby but did not process the conditions in the same way for themselves.

A phenomenological study of the lived experience of women with GDM pregnancies had a similar finding where participants prioritized the requirements of baby over their own needs (Evans & O'Brien, 2005). Baby first adds a new dimension to the literature on illness perceptions and health behaviour change. Previous studies using the CSM as a framework for illness perceptions have focused on how people perceive severity and consequences of illnesses with respect to how it impacts the individual and those around them, not others inside them (Hagger & Orbell, 2003). Previous evidence also suggests that the perceived severity of an illness influences behaviour change (Champion & Skinner, 2008). If severity is wrapped up in a "baby first" mentality, it could be argued that when a woman delivers her baby, if the baby is healthy, the perceived severity of her illness would likely decline or disappear. Therefore, the

perception of long-term risk associated with the pregnancy condition is likely not a big driver of behaviour change.

A likely contributor to the “baby first” mindset could be related to health care interactions. A recent qualitative study found that women felt their health care teams communicated that the mothers’ efforts to manage their GDM pregnancy was for baby only, not for the women themselves. One woman described the feeling that she was having the baby “for the hospital, not for her” (Parsons et al., 2018). Furthermore, decades of public health interventions for smoking cessation in pregnancy have been criticized for their fetal-centric, mother-blaming approach (Greaves, Hemsing, Poole, Bialystok, & O’Leary, 2016). Perhaps the not-so-subtle message that HCPs primarily care about outcomes to baby might have influenced the women’s risk focus on baby primarily.

When considering the consequences of their pregnancy conditions, the women in the present study were able to conceptualize their future risk with developing conditions in subsequent pregnancies more readily than their future risk of chronic disease like CVD and T2DM. This finding aligns with other recent studies. Traylor et al. (2016) reported that women with hypertensive disorders of pregnancy could foresee hypertension in subsequent pregnancies as a risk more readily than future chronic hypertension or other cardiovascular conditions like myocardial infarction. Also, a qualitative exploration of the experiences of women in the United Kingdom with a history of preeclampsia found that when women thought of their future health risk, they were mostly interested in their health for subsequent pregnancies (Brown et al., 2013).

Although the “baby first” mentality might initially serve as a barrier by distracting women from their own self-care, long-term it also could serve as a facilitator in the form of modeling. When women in the present study considered health promoting behaviours for their

own personal health, they were mostly motivated by the wish to be positive role models and to have adequate vitality to keep up with their kids. This finding was consistent with the narrative in the literature that pregnancy serves as a “window of opportunity” for health teaching (Smith et al., 2013). It was also consistent with the findings from Eades et al. (2018) that women’s lifestyle changes were primarily for their baby’s health, however these changes were not sustained in the postpartum period. Despite the change in circumstances and barriers created by parenting, modelling behaviour seems to be a way to motivate women. Evidence suggests that maternal modeling of healthy behaviours like physical activity is positively correlated with physical activity in children (Schoeppe et al., 2016). However, the intention to model healthy behaviours and its influence on a mother’s health behaviour has not been studied extensively.

**Implications for practice.** Clinicians can recognize that women conceptualize their pregnancy conditions in terms of how they impact their baby, not themselves. As a response to years of failed smoking cessation interventions in pregnancy, it has been argued that a paradigm shift is needed to a focus on mother’s health “for its own sake” in preconception, throughout pregnancy and postpartum (Greaves et al., 2016). This shift must also recognize that a woman’s health is determined by social determinants such as poverty, violence, and education (Greaves et al., 2016). Also, this study provides evidence to suggest that postpartum risk clinics could make a point of highlighting the goal of risk mitigation in subsequent pregnancies as a means of increasing attendance and subsequent motivation around short-term health-promoting behaviour. The next area for discussion will move from women’s perceptions of their pregnancy conditions to women’s views on future risk.

**Susceptibility to future risk.** The women in the present study saw their future risk of chronic disease more readily if they had family history of these conditions. The women with

family history of either Type 2 Diabetes (T2DM) or cardiovascular disease (CVD) saw themselves as susceptible to these conditions in the future. A study in the U.K. of the perceptions of women with a recent history of preeclampsia also found that only the women with a family history of CVD saw themselves as vulnerable to this future condition (Brown, Bell, Collins, Waring, Robson & Finch, 2012). However, another study found that only approximately half of people with familial history of T2DM believed that they were susceptible to the disease (Dorman et al., 2012). The CSM views family history as an example of concrete information that can influence perceptions of an illness threat (Hagger & Orbell, 2003). Women with direct experiences of a family member with a health condition like CVD might appraise the efficacy of their family's coping methods (subconsciously or consciously). This, in turn, might influence their own behavioural response to the news of their increased risk.

Future risk perceptions also seemed to be influenced by the type and/or severity of pregnancy condition experienced. Only two women out of the six in my sample with GDM mentioned they were at increased risk for CVD, yet all women with GDM knew of their risk for T2DM. This finding aligns with a recent study in Norway where only one of ten women with GDM were aware of their future CVD risk, whereas eight women were aware of their risk for Type 2 Diabetes (Sandsaeter et al., 2019). Furthermore, a study by Traylor et al. (2016) found that risk perceptions postpartum after a hypertensive pregnancy were more accurate with increased severity of the pregnancy condition and preterm delivery.

Risk knowledge was also influenced by access to the formal postpartum CVD risk clinic. All the women who attended the postpartum risk clinic mentioned CVD as a future risk. Only one of five of the women who received routine prenatal and postpartum care mentioned her future CVD risk. This finding aligns with a previous study in the United States of America that

found that women who received routine prenatal care did not see their preeclampsia in pregnancy as a risk factor for CVD (Seely et al., 2013). Women's views of the length of their conditions also influenced their views of future health projections.

**Timeline.** The women in the present study all felt that their health condition had ended upon delivery of their baby. While this is true medically in most instances, their conditions could be considered chronic given the high likelihood for future chronic conditions. Similar findings were reported by Eades and colleagues (2018), where women saw GDM as being short-lived and consequences as minimal. Perceived timeline of illnesses has been discussed in previous CSM literature and it has been found that it influences adherence to treatment and health outcomes. In a study with people with diabetes, the belief that the illness is cyclical reduced compliance with medications and diet advice (Cameron & Moss-Morris, 2010). If the women do not recognize the chronicity of their condition, especially when considering GDM, where there is a 60% chance of developing it in future pregnancies, and instead see it as cyclical, they could be less likely to engage in preventative health behaviours. Depression research has also found that people who view depression as cyclical are less likely to seek treatment versus those who see it as a chronic condition (McAndrew et al., 2018).

Furthermore, many women still saw chronic conditions associated with their condition of pregnancy like T2DM as something that would happen far into the future. When some women considered the future chronic illnesses associated with their pregnancy conditions, they expected that these conditions would come up when they were old. This was also described by Eades et al. (2018) where women misunderstood the timeline of risk for T2DM. When, evidence suggests that future illnesses like T2DM will come up much sooner, often within ten years after delivery for GDM (Kitzmilller, Dang-Kilduff & Taslimi, 2007). Susceptibility to future chronic disease



risk seems to be influenced by family history, type and severity of condition, and access to formal counselling on future risk projections.

However, it can also be argued from a lay perspective of risk that viewing conditions of pregnancy as chronic extends medicine's gaze into women's lives beyond pregnancy and further pathologizes women's bodies. This has occurred in other situations in medicine, such as the pathologizing of fat bodies, where obesity is now considered a chronic disease (Wharton et al., 2020). Whether carrying and internalizing a risk profile beyond pregnancy is realistic or helpful for most women is debatable.

**Implications for practice.** It is important to seek common understanding of what women see as valuable coping for their conditions. It is also crucial to avoid judgment if this coping does not align with medical recommendations. Education for both HCPs and patients so there is more recognition of the relatively short timeline for development of chronic illnesses after pregnancy is warranted. Also, better transitions of care to primary care providers is needed, especially for communities that lack postpartum risk clinics, so future condition risk is considered and on-going screening occurs. Stories of hope and silver linings from GDM pregnancies will be discussed next.

**Blessing in disguise.** A significant portion of the women with GDM expressed that their condition was, as one woman described it, "a blessing in disguise". The women experienced their GDM diagnosis as an opportunity to prioritize and seek support for their health. Some women viewed their pregnancy condition as an awareness-builder or reminder of their future chronic disease risk that was already on their radar. In addition, the pregnancy conditions served as a gateway to accessing other important mental health supports. A recent qualitative study on the experiences of an ethnically diverse sample of women with GDM reported similar optimistic

experiences. Some women saw their diagnoses as a “wake-up call” and reported feeling more motivated to adjust their health behaviours to prevent T2DM (Kaptein et al., 2015). A comparable finding was also discussed in a large Australian study with written accounts from almost 400 women. This study reported that about 10 percent of women in their sample saw their pregnancy condition as a positive opportunity to change their lifestyle but this experience did not seem to hold true for younger women or women who had GDM in a previous pregnancy (Morrison, Lowe & Collins, 2014). Evans and O’Brien (2005) described the GDM experience as “transformative” in terms of the women’s orientation toward their future health.

The experience of women embracing mental health support as a result of their high-risk pregnancies has not been widely discussed in previous literature. The literature is, however, vast on the high prevalence of mood disorders in the perinatal and postpartum life period (Howard, Molyneaux, Dennis, Rochat, Stein & Milgrom, 2014). However, a recent Australian study (with free universal health care access like Canada) found that women who are offered mental health support in pregnancy often do not engage in this type of service. Of women who were offered a mental health appointment, less than half attended (Ayres et al., 2019).

**Implications for practice.** The blessing in disguise accounts support previous assumptions that pregnancy is an opportune time to support women in health-promoting behaviours. It also supports clinicians routinely offering mental health support to patients who are experiencing risky pregnancies. Because most women often do not engage in mental health support in health care, women with high risk pregnancies might present as a sub-population who is more open and willing to access mental health supports. Next, this paper will move beyond health perceptions and discuss the contextual and environmental barriers and facilitators to enacting health related self-care.

**Risk as inequitably distributed.** Underpinning many barriers and facilitators to health that were discussed was social determinants of health (SDH) and social support. SDH, as described by the women in the present study, represent examples of how risk does not begin or end with the women's bodies. Risk is unequally distributed. There are inherent risks *to* women throughout their lifespan based on their social position and historical context. SDH such as income, transportation, and employment situations have been documented extensively in the literature as a major influence on public health (Adler et al., 2016). One SDH of interest in the present study was the challenges of cultural displacement. The cultural challenges to follow a GDM-friendly diet, and specifically limiting rice consumption, was also described by women in the qualitative study by Kaptein et al. (2015) on GDM experiences. Furthermore, social support was cited as a major barrier for one participant who's family lives in her native country. Social support has also been discussed extensively elsewhere as a potent facilitator to health-promoting behaviour. A recent qualitative study of women who experienced GDM in pregnancy found that social support was important throughout the prenatal and early postpartum experience (Carolan, 2012). Women without adequate social support likely will benefit even more from "wrap-around care" in the prenatal and postpartum period.

**A case for wrap-around care.** One participant who did not have access to the same level of social support as others in the present study's sample, seemed to embrace all the service that was offered to her at her pregnancy clinic. P1 described how she was more open to mental health counselling and support because of her GDM pregnancy. The pregnancy condition served as "one more thing" on top of other life pressures and she no longer felt she could manage on her own. Furthermore, when she and her loved ones became worried about her mood postpartum, she was comfortable sharing with her prenatal physician team and sought out treatment. Because

of the rapport she built with the mental health team antenatally, she also took advantage of a postpartum support group. She attributed her pregnancy experience, and the care she received, as a contributor to her state of wellness at her follow-up appointment. This case study demonstrates the importance of wrap-around care for women both antenatally and postpartum. Other studies have highlighted a sense of abandonment for women postpartum (Parsons et al., 2018), perhaps part of this experience has to do with the level of rapport built prenatally so that women feel comfortable in seeking out care after the baby is born.

**Implications for practice.** The present study suggests that high-risk pregnancy conditions could be a unique gateway to mental health support. Women who would not otherwise access this support might do so if the service is offered as part of wrap-around care for a pregnancy condition. Clinicians can assess and offer mental health support to women who have been diagnosed with conditions in pregnancy at multiple time points. Because of the additional stress associated with these conditions, there might be increased uptake and services might be better received compared to the general pregnant population. Also, it is important that these services are offered postpartum for women who were diagnosed and delivered quite quickly. As mentioned above, these women might need more time to come to terms with traumatic pregnancies and recognize the need for additional support. Wrap-around care aligns with models that advocate for a whole systems approach to care. Kennedy and Rogers (2001) described and evaluated an effective nursing model that encourages patient self-determination, HCP-patient-community partnership in all stages of health services.

**Medicine's role in risk.** This study highlighted the role of medicine in communicating and intervening on risk as well as women's agency in seeking support for their health both during their pregnancy and during their postpartum journey. The participants' views on

communication with health care providers (HCPs) and quotes about the short and long-term risks associated with their conditions of pregnancy were summarized into three main areas. Women discussed the timing of the information provided, the medium of information and the content of the risk discussions.

**Timing.** Many participants wished they had been more prepared for their pregnancy condition diagnoses through early conversations about possible risks and symptoms to watch out for. A similar finding was discussed in a study by Parsons et al. (2018) where participants desired an earlier warning about their GDM risk. These women felt more preparation would have lessened the surprise of their diagnoses and allow for more time to make lifestyle changes. Preparation also came up for women regarding possible implications and treatment plans for their pregnancy conditions.

After women were diagnosed with their conditions of pregnancy, timing of short and long-term risk information was also discussed. Women had differing views as to when is an ideal time to inform them of future risk. Some women desired this discussion to be layered at multiple time points of their pregnancy and postpartum journey. Timing was also discussed by Brown et al. (2012), where women with a history of preeclampsia viewed eight to ten weeks postpartum as too early for future risk discussions and instead preferred a six-month follow-up. Future studies could ask a representative sample of the population of interest for a better understanding of women's views on timing of risk information.

**Medium.** When women did not receive adequate information or support from their health care team, they went elsewhere for answers. The medium in which women received information about their conditions and their associated risk that was most discussed in the present study was, not surprisingly, online. Women often found internet searches helpful, but

also warned of some of the impacts to emotional health from worst-case scenario discussions online. A recent systematic review of internet searches by pregnant women found that pregnancy complications was one of the most common topics searched (Sayakhot & Carolan-Olah, 2016). The study also found that although most women find online information useful, they rarely share the content of their online searches with their health care teams (Sayakhot & Carolan-Olah, 2016). This lack of communication leaves little room for health care providers to dispel myths, answer questions or discuss concerns that might arise. It is unclear why women are not discussing their online searches with their HCPs. One future research direction could include a document analysis of posts online from women with high risk pregnancies to better understand what questions are being asked and what is not being addressed well in health care appointments. A common online experience cited by participants was peer to peer discussions.

Peer-support online was discussed at length in the present study, mainly by women living with GDM. A study by Savakhot and Carolan-Olah (2016) also discussed how internet searches can improve confidence for women, and it seems the goal of internet searches might be less about information-seeking and more about building self-efficacy and a sense of social support. Diabetes communities amongst lay people are extensive in the cyber world. Known as diabetes online communities (DOCs), these networks have been studied and were reviewed elsewhere (Hilliard, Sparling, Hitchcock, Oser & Hood, 2015). However, there is a paucity of data addressing gestational diabetes communities, specifically. Participants have previously indicated their preference for postpartum health promotion interventions online due to their accessible nature. For example, a recent systematic review of qualitative studies found that across several studies, digital health interventions for lifestyle management in the postpartum period was highly acceptable among the women for which this service would be targeted (Lim, Tan, Madden &

Hill, 2019). Peer support for women with diabetes in the postpartum period was addressed by Friedman, Niznik, Bolden and Yee (2016) where the authors found that participants were interested to this type of connection. More research is warranted to understand how women with health conditions in pregnancy use online communities to make sense of their risk and seek support. The medium most commonly used by participants to make sense of their conditions and risk was clearly online. Next, the women's experiences with the content of risk information will be explored.

**Content.** For the women who attended the postpartum risk clinic, risk discussions at this clinic involved the calculation and presentation of quantitative risk scores based on the women's biometric profiles. The women who received usual prenatal care, on the other hand, felt they did not have the opportunity for adequate risk dialogues and were left with many unanswered questions. Postpartum abandonment was also discussed by Parsons et al. (2018). With the lack of information from her health care team, one participant in the present study described a missed opportunity from her HCP to discuss future risk postpartum. She instead sought out information from her peers online about future risk. After reading about peer views and experiences on this topic, she felt little personal control for prevention of future GDM pregnancies and felt GDM in future pregnancies was inevitable. Also, in a recent study on GDM and preeclampsia in a Norwegian health care setting, women reported a desire for postpartum future risk discussions and lifestyle modification advice to take place with their partners so this message could be reinforced at home (Sandsaeter et al., 2019). This is an example of a systems approach to care.

What is not clear is if the women were told about CVD risk but did not remember this discussion or if HCPs did not mention it. Many care providers are not aware of the heightened risk associated with pregnancy conditions. A recent survey of over 500 Canadian physicians

found that only approximately half of the respondents were aware of the link between pregnancy complications and heart disease (McDonnell et al., 2018). In addition, research shows that even when HCPs are familiar with the evidence on future risk associations with pregnancy conditions, they do not necessarily communicate this information with patients. For example, a Canadian study found that although 50% of prenatal care providers were aware of the link between hypertensive disorders of pregnancy and chronic hypertension, only 10% communicated this to patients (MacDonald et al., 2007). Furthermore, postpartum screening for diabetes remains very low- 14% for usual care, 28% with 6-month reminders (Shea et al., 2011). More data as to why this occurs is needed. The next area of content regarding risk is related to treatment decisions in the prenatal period that are meant to reduce risk of complications in labour.

**Lack of shared decision-making.** Many participants described the treatment decision to induce labour (IOL) early as confusing and not based on two-way conversations. The short-term risks to baby associated with IOL were a concern for many participants. The women discussed a lack of opportunity to discuss the pros and cons of early induction with their health care teams. Many clinical practice guidelines and research articles present evidence of improved birth outcomes, including lower rates of C-sections by inducing labour early (38-39 weeks) for gestational diabetes (Melamed et al., 2016). Induction of labour for preeclampsia and gestational hypertension is associated with lower rates of maternal and neonatal morbidity and mortality (Coates et al., 2020). Interestingly, there was a notable absence of discussion from any of the women in the present study about delivering a stillborn baby as a serious consequence of these conditions and a reason to induce early. It is unclear if HCPs are not mentioning these more severe risks or if patients just did not recall these discussions.



However, it is important to note that there are also risks associated with health care treatments. This risk is evidenced by the accounts from women in the present study of misdiagnosis, HCPs not listening to women when their intuition was telling them something was wrong, and post-delivery time spent in the NICU. It has been argued that the practice of assessing women and assigning them a risk category is based on a growing culture of control of pregnancies in order to avoid the threat of litigation (Mackenzie, Bryers & Teijiengen, 2010). There are risks associated with early induction of labour including neonatal jaundice and hypoglycemia (Coates et al., 2020). Furthermore, IOL leads to increased pain in labour and more medical interventions (Jay, Thomas & Brooks, 2018). Interestingly, a qualitative study of obstetricians' and midwives' perspectives on their experiences with IOL found that the participants often appropriated women's autonomy in decision-making by highlighting the pros or the risks of IOL based on their clinical judgement of the situation (Nippita, Porter, Seeho, Morris, & Roberts). The providers also felt that more education, including written information, earlier in the prenatal period about IOL and other aspects of childbirth would be beneficial to mitigate their lack of time in clinical encounters (Nippita, Porter, Seeho, Morris, & Roberts). Other studies have also found that IOL is often planned without enough discussion with patients (Jay, Thomas & Brooks, 2018).

**Medicine's role in risk- implications for practice.** Earlier discussions regarding possible issues that can come up in pregnancy might mitigate some of the initial negative emotional responses that come with diagnoses and allow for sooner lifestyle amelioration. Because it is not always clear who might end up with certain conditions, perhaps as part of first prenatal discussions, the most common complications of pregnancy and their symptoms could be addressed. For timing of future risk conversations, this study provides evidence for a layered

approach at multiple time points, including at diagnosis, as part of discharge planning, and at a six-month postpartum debrief.

This study also provides evidence that HCPs can mitigate risk and optimize online advice by explicitly inviting pregnant and postpartum patients, in a curious and non-judgemental manner, about their internet use as it relates to their health care. Open discussions about online searches might improve communication and women's sense of confidence in their role in their prenatal journey with a health condition. Furthermore, intervention programs could include an element of HCP moderation in peer support groups. An online forum with HCP presence could be an opportunity for women to share stories, have their questions answered and hear more balanced perspectives on risk. This could reduce some of the anxiety women feel when they hear worst-case scenario stories online. This moderation would have to be sensitive and responsive to peer groups' perceived needs so these online spaces can remain safe for sharing and open discourse among the users. The women's views on timing, medium and content of risk communication all provided considerations for future research and HCP practice.

### **Study Advantages and Limitations**

The present study had notable strengths and limitations. A strength included the open-ended nature of interviews that allowed women to share their lived experiences. As previously mentioned, heart disease outcomes are inequitable for women, yet the discourse is often limited when it comes to women patient perspectives. In addition, we noticed that participants were able to self-reflect in the interviews and came to a novel position of understanding about their personal experiences by the end of their interviews. As an example, P10 reflected to me after her interview that the interview served as an opportunity for her to debrief about her pregnancy experience for the first time. Also, as described in the "blessing in disguise" theme, P1 came to a

new understanding about her condition's role in her seeking mental health support. As mentioned in my reflexivity section, another strength was my ability to build rapport with patients, which was related to years of counselling experience as a clinician.

Some of the limitations to this study included a negative impact on building rapport with women who I interviewed over the phone. This mode of communication restricted my ability to demonstrate, through body language, cues of empathy and understanding. Another potential limitation of the study was the inability to recruit many women of lower socioeconomic status. It is known from previous research, this group is less likely to engage in postpartum clinics that address future risk (Smith et al., 2013). Our ethics only permitted recruitment via a letter for our second site. I expect that well-resourced people were more likely to respond to a letter without an in-person request. Ideally, it would have been better to recruit in a similar way as location one, where clinicians were able to ask women to participate in person. Furthermore, in order to prevent unnecessary emotional hardship of news about health risks, as per ethics, I was not permitted to explicitly ask about future risk unless the participants mentioned it first. This served as an interesting area for analysis as the absence of this discussion by participants was also data to explore. Both strengths and limitations were reflected on throughout the research process.

### **Conclusion**

It has been suggested that conditions of pregnancy provide a window of opportunity for discussion around future CVD risk. This study highlighted possible support for such a perspective, but also the problems associated with using one perspective of risk as a focal point for discussion. The discourse to date regarding conditions of pregnancy and the chronic disease link includes the commonly cited term 'pregnancy is a stress-test'. This view inserts medicine into a natural part of human experience and functioning and likens pregnancy to a medical

diagnostic procedure. This study broadened the medical paradigm of risk as located in the woman's body and situated risk as also coming from women's worlds and from medicine itself. Participants' lay perspectives of risk and illness representations, including emotional responses, causal attributions, perceived severity and consequences were explored. Prominent themes included illness narratives, causal attributions that resulted in self-blame, consequences of conditions that were focused on baby, blessing in disguise, and inequitable risk allocation. Also, women's experiences with medical risk communication and intervention were explored. Practice and research implications were discussed. The study aimed to inspire reflexivity in health care providers who serve the women of interest and to inform future research in the area of pregnancy and chronic disease risk that is rooted in the perspectives of consumers of health care.

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## Appendix A- Script for Recruitment

Department of Psychology  
1600 Westbank Drive  
Peterborough ON  
K9J7B8

Contact: Krystal LeBreton, MHSc, RD, CDE  
Supervisor: Fergal O'Hagan, PHD 705-748-1011 # 7086

"Perception of risky pregnancies- impact on behaviour change attitudes in postpartum period "

Script for what will be communicated to Partners in Pregnancy Staff (Registered Nurses, Physician Assistant, and Doctors) who will provide initial recruitment letter to patients at their 6-week postpartum visit.

Thank you to all of you for your help and support with recruiting women to the study that I will use for my Health Psychology MSc Thesis project. The process for recruitment will be:

- 1) At the patient's baby visit- those who are eligible for the study will be flagged in the chart using the baby stamp in the EMR (the stamp will include one line that states the patient's condition and their increased risk for future premature cardiometabolic disease).
- 2) The conditions of interest are: gestational diabetes, hypertension in pregnancy (including preeclampsia), small for gestational age baby (<2500g at delivery), preterm labour (<37 weeks), and/or clinically significant abruption.  
  - \*\*please use your clinical judgement for who you invite. If a patient's pregnancy condition seems like an anomaly and not likely related to future premature CVD risk, you do not need to invite this person.
- 3) The inclusion criteria for my study are:
  - delivery within the past 2 years
  - one or more of the above conditions of pregnancy/ delivery
  - 20-40 years old
 The exclusion criteria are:
  - Neonatal or postpartum loss in their most recent pregnancy
  - Unmanaged postpartum depression or mood disorder
  - On-going acute health issues at the time of recruitment
  - On-going unmanaged substance addiction
- 4) At the 6-week check, those who meet the inclusion criteria and do not have any of the exclusion criteria can be offered an invitation to participate in the study (see attached invitation to give to participants). The invitations will be in an envelope at the nurses station.
- 5) Ideally, ask patients to fill out the invitation sheet with their name and contact info. If they are unsure they can keep the invitation with my contact info and contact me later. Their signature does not mean they are in the study, just that they are consenting to learning more about the study before deciding if they would like to take part.

- 6) There is a folder in the NRT locked cabinet for completed invitations. I will clear these out often but for the days I am not at PIPC they need to be in a locked space. The key to the NRT cupboard is in the top drawer of the cabinet by my desk.
- 7) Please send a message to me via the emr so people are not asked twice. This shouldn't be an issue as they will not likely be coming back after their 6 week check.
- 8) We will ideally purposively sample across SES, family composition, and gravidity/parity to get a range of experiences. I will check in with the team if I find our sample is too homogeneous in demographic profile.
- 9) If you have any questions please don't hesitate to ask me!

Thanks again!!

Krystal

## Appendix B- Consent to Contact

Department of Psychology

1600 Westbank Drive

Peterborough ON

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Contact: Krystal LeBreton, MHS, RD, CDE

Supervisor: Fergal O'Hagan, PHD 705-748-1011 # 7086

### Invitation to Join Study- Partners in Pregnancy 6-week Check

Congratulations on your new baby! Because you experienced a health condition or complication in your recent pregnancy or delivery, you are eligible to participate in a study being conducted by researchers at Trent University. In this study, researchers are interested in your views and experience(s) with your pregnancy condition and your experience with communication about this condition from health care providers. Your participation and valuable feedback will contribute to more helpful conversations about health conditions in pregnancy. Health care providers don't always understand the perspective of patients and don't have time to ask. This is your chance to share your stories to improve care. We are requesting a 1-1.5 hour interview (either in person or over the phone or skype) and a second shorter follow-up interview for 30-45 minutes. You will be entered into a draw for a \$50 gift card at Belly's and Baby's in Peterborough. You will also be compensated with a day bus pass and childcare costs if needed.

Please sign here if you agree to being contacted by a researcher to learn more about this exciting project:

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

Name: \_\_\_\_\_

Phone Number or email: \_\_\_\_\_

Best times/ days to reach you: \_\_\_\_\_

Or you can reach the researcher at: [krystallebreton@trentu.ca](mailto:krystallebreton@trentu.ca) or

## **Appendix C- Information and Consent Form**

Department of Psychology  
1600 Westbank Drive  
Peterborough ON  
K9J7B8

Contact: Krystal LeBreton, MHS, RD, CDE  
Supervisor: Fergal O'Hagan, PHD 705-748-1011 # 7086

"Mothers' Experiences and Perceptions of Pregnancy Conditions"

Thank you for your interest in our study!

Purpose: The purpose of the study is to understand the experiences of women and their perceptions of their health conditions in pregnancy (such as: gestational diabetes, hypertension, or preterm deliveries). Researchers also hope to learn about how your health care team communicated with you about your condition in pregnancy. As a woman having experience with a health condition during pregnancy, your experiences will help with future care of pregnant patients. Please read on to understand your involvement in the study.

Description of the Study: You will be asked to complete 1 interview that will last approximately 1-1.5 hours. Another follow up interview will be requested 4 weeks later to clarify things that came out of the first interview and will last approximately 45 minutes. All interviews will be tape-recorded if you agree. The interviews will ask you about your understanding of your previous pregnancy condition, and how it impacted your health. Throughout the study you will be given the chance to ask questions about your participation.

Benefits: There will be no direct gain for taking part in this study apart from aiding in building understanding of patient perspectives in the prenatal period. The results of this study will provide information for health care providers on how best to communicate about these conditions.

Potential Harm: An unlikely risk of participation is emotional distress over discussing challenges of your pregnancy. If you find the interview distressing and would like some support, your interviewer, Krystal, can help you to contact a support phone line or counselling services in your area. For Peterborough call: 1-866-995-9933 and for Kingston call: 1-866-616-6005 for 24-hour free, confidential crisis support. You have the right to choose what to share in the interview and to choose not to answer certain questions.

Confidentiality: Your involvement in the study will not be revealed to anyone but the researchers. Strict confidentiality will be respected and no information regarding identity will ever appear in any publications or presentations. Specifically, the research team will maintain confidentiality by removing name and other identifying information from the transcript and exclude name from written reports.

Participation: Participation is entirely voluntary and you have the right to refuse to participate or to freely withdraw from this study at any time during its course. There are no negative consequences from withdrawing from the study at any time. Your data will also be withdrawn from the study unless you give permission to still use it.

Information Storage: You understand that the researchers will store any information gathered from you in a secure cabinet and laboratory at Trent University that only they will have

access to. You understand that any computer files containing my information will be secured with passwords and stored on secure computers. Any computer files sent over electronic media will be encrypted. Any data with personal information will be encrypted. After five years, data will be destroyed.

Use of Information: You understand that this information will be used in reports, presentations, and journal articles. This information may be used to develop subsequent theories, programs, or practices to improve prenatal health communication.

Conflict of Interest: You understand that the researchers have no commercial interest in completing this study. You also understand that this study is not funded by any commercial interest.

Consent: The research study and procedures have been explained to you and any of your questions have been answered to your satisfaction. The potential harms have been explained to you and you also understand the benefits to taking part in this study. You know that you may ask now, or in the future, any questions that you have about the study or the research procedures. You have been assured that no information will be released or printed that would disclose your personal identity.

Limits to Confidentiality: You understand that if harm to self or others or abuse of children is disclosed, researchers have a legal duty to report this information.

If you have questions about the study you can contact the researcher listed at the top of this page. This study has been reviewed and approved by the Trent University Research Ethics Board. Please direct questions pertaining to this review to Karen Mauro, Certifications and Regulatory Compliance Officer, Trent University, Phone: 705-748-1011 ext 7896, Email: kmauro@trentu.ca. You will be provided with a copy of this consent form for your records.

Participant Name:

Signature:

Date:



## Appendix D- Debrief Letter

Department of Psychology  
 1600 Westbank Drive  
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 Contact: Krystal LeBreton, MHSc, RD, CDE  
 Supervisor: Fergal O'Hagan, PHD 705-748-1011 # 7086

"Mothers' Experiences and Perceptions of Pregnancy Conditions"

### Debrief Letter for Participants

Thank you for participating in this study. Your time and effort are very much appreciated.

We are interested in understanding the experience of women who have developed certain conditions in pregnancy including gestational diabetes, hypertension in pregnancy, small for gestational age baby, abruption and/or preterm labour. We want to know what these conditions mean to women and how women see them impacting their health and well-being. We are also interested in how these conditions influenced lifestyle behaviour during and/or after pregnancy.

We are interested in women's understanding of their pregnancy/ early postpartum condition(s) and how they see it influencing their lives. We hope to gather new insight as to what kind of conversation about these conditions and their associated risk is helpful and what is potentially harmful. How can healthcare providers support women to increase awareness and appreciation of the importance of engaging in healthy behaviours during and after pregnancy? When is the ideal time to have this conversation with women?

Through this research, we hope to inform and improve health care practices around helping women manage these conditions more effectively. In generously sharing your experiences, you will help us meet this objective.

If you would like a copy of the summary of the study please provide your name and phone number here: \_\_\_\_\_

OR email Krystal at: [krystallebreton@trentu.ca](mailto:krystallebreton@trentu.ca)

This study has been reviewed and approved by the Trent University Research Ethics Board. Please direct questions pertaining to this review to Karen Mauro, Certifications and Regulatory Compliance Officer, Trent University, Phone: 705-748-1011 ext 7896, Email: [kmaro@trentu.ca](mailto:kmaro@trentu.ca)

## Appendix E

Department of Psychology  
1600 Westbank Drive  
Peterborough ON, K9J7B8  
Contact: Krystal LeBreton, MHSc, RD, CDE  
Supervisor: Fergal O'Hagan, PHD 705-748-1011 # 7086

Hi [Insert Name];

We hope that this letter finds you, [insert child's name], and your entire family in good health and spirits! You are being contacted because you attended the Maternal Health Clinic after the birth of your baby to learn more about how your health condition in pregnancy might impact your future health.

We would like to share a study opportunity with you. Researchers at Trent University are interested in your perspective and experience of your pregnancy condition and how this condition was discussed with you by your health team. Health care providers don't always understand the perspective of patients and they don't always have time to ask. This is your chance to share your experiences and stories so women can receive better care prenatally and postpartum. If you had your baby within the past 2 years, are between the ages of 20-40, please read on!

We are requesting a 1-1.5 hour interview (either in person or over the phone or skype) and a second shorter follow-up interview for 30-45 minutes. For your time, will be entered in a draw for a \$50 gift card at Walmart and will be provided with childcare expenses and transportation if needed. We would love to hear from you!

Please email Krystal LeBreton (Masters student in Health Psychology at Trent University) at: [krystallebreton@trentu.ca](mailto:krystallebreton@trentu.ca) with the subject "Study" to learn more. You can also leave a message by phone with Krystal's supervisor Fergal O'Hagan if that's easier at: **705-748-1011 extension: 7086**. **Note:** You will not be able to participate if you are currently experiencing unmanaged mental or physical health issues or experienced a loss of your baby, as this study might cause unnecessary distress.

Please let me know if you prefer a phone call or email and what is the best time to reach you. By contacting us you are not consenting to participating, you will just be given more information about the study.

Thanks for your time and consideration!!

Warm Regards, Krystal

## Appendix F- Interview Schedule

### Introduction/ Consent Review

Hello and welcome! Thanks so much for taking the time out of your busy life to take part in this research study. We have already gone over consent over the phone but just reiterate- this interview will be recorded. Are you still agreeable to this? Do you have any questions or concerns at this point? Please feel free to ask questions if anything comes up throughout the interview and if you need a break just let me know. The interview will take approximately 1 hour to 90 minutes.

### Demographics

First of all, I would like to go over a few demographic questions.

How old are you?

Do you currently have a job?

How much education did you receive? (high school, undergrad, graduate school or professional degree)

How many children do you have?

When did you deliver your last baby? What is your baby's name?

Are you in a committed relationship? If yes, how long have you been together?

Do you have access to health benefits?

What was the health condition in pregnancy that made you eligible for this study?

Background/ Rapport-Building

Tell me what made you interested in participating in this study?

What is health to you? what does it mean?

Tell me about gestational diabetes.

Follow-up: What is **gestational diabetes**?

Where did it come from?

It's not always easy to know who will get conditions like this. What are your thoughts on where this illness came from?

Prompt: How do you think you got this illness?

Prompt: Tell me about your ideas of what contributed to your getting this condition while others did not?

Elicit a Narrative- Chronological experience of Condition/ Communication with healthcare Providers

Tell me about the diagnosis and everything you can remember. What was that like?

How did you feel in that first conversation?

Did your health care providers or anyone else discuss this condition with you? In what manner? What was that like?

Tell me more about that.

Prompt: If the participant mentions diabetes/ heart disease- add "What does diabetes or heart disease mean to you?"

What were future visits to healthcare providers like?

Self Care

How did you view your health before you were diagnosed with **gestational diabetes**?  
How did the condition change your view of your health?

How did you view self care before **gestational diabetes** and has this changed? If so, how?

Condition Management

Sometimes people find it challenging to manage **gestational diabetes**. How did you manage your condition?

How did **gestational diabetes** affect you?

Prompts

Physical health? Your baby's health? How does it affect your health now?

How did this condition affect you emotionally? How does it impact your emotions now?

How did you manage your emotions during this condition?

How did the condition affect your life? Does it continue to affect your life?

Prompt- finances? socializing? work?

Perceived Severity

Did you consider (or talk to anyone) about how to prevent this condition prior to getting pregnant or during your pregnancy? Tell me about that.

In your opinion, how severe or serious was your condition?

Who (if anyone) did you discuss this condition with in your life?

Prompt: natural practitioners? Partner? family? friends? How did they perceive your condition?

Prompt: was anything unhelpful from your partner (or other support people)?

Timeline of Condition/ Future Risk

How long do you feel this health condition will last? Or how long did it last?

Do you have thoughts about how you could prevent this condition in future pregnancies (if you plan to have more children)?

For those participants who bring up future risk of heart disease or diabetes

What are your thoughts on some ways to help prevent this condition in the future?

Are you currently working on a health lifestyle change? What has made you choose to work on this?

If yes, can you tell me about it? What would you find helpful in the postpartum period to help with lifestyle changes?

Prompt with buffet of options- fitness facility membership; online support group; dietary education; reminder calls; access to an exercise specialist; in-person support group; anything else I haven't thought of that might be helpful?

Follow up Question: What are some things you see getting in the way of you being able to take part in a program/ activity in the community that you might find helpful with lifestyle change?

Follow up Q: Have you accessed anything already in the community to help with this health goal?

Those who attended the Maternal Health Clinic: Add:

Tell me about what made you decide to attend the Maternal Health Clinic?

How was future risk addressed at this clinic? What was helpful? What was not helpful?