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The Experience of Waiting Among Women with Vaginal Bleeding During Early Pregnancy

by

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Dedication

To my husband Ryan, son Layne and baby-to-be

For always knowing I would accomplish this even when I did not

Abstract

Bleeding during pregnancy affects as many as one in four pregnancies with roughly half of these resulting in pregnancy loss. An interpretive descriptive design was employed to explore the research question: "How do women with bleeding in early pregnancy describe their experience of waiting in the emergency department?" The essence of the experience of waiting while pregnant with bleeding was the interplay of uncertainty and waiting and how this experience was shaped by mediating factors such as previous experience, staff attitudes, social support, information provision, and lack of privacy. Implications for improving the care of women experiencing bleeding during early pregnancy are provided. The findings of this project contribute to our understanding of the experience of waiting in the context of early pregnancy, underscore the implication of this experience on women to their health care providers, and point the way to improving women's overall satisfaction with their care.

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Chapter One

Introduction

As many as one quarter of women may experience bleeding during pregnancy with roughly half of these progressing to pregnancy loss (Everett, 1997; Hasan et al., 2009). To put this in perspective, of the 447,485 recorded pregnancies in Canada in 2005, bleeding during pregnancy potentially affected over 110, 000 women. (Statistics Canada, 2005). Lack of access to primary care and the fear and anxiety associated with their symptoms results in many pregnant women experiencing bleeding to present at emergency departments (Bacidore, Warren, Chaput, & Keough, 2009).

The researcher was employed in a busy emergency department of a hospital with a large maternity center; women who are less than 20 weeks gestation who experience bleeding often present to the emergency department. The number of women experiencing vaginal bleeding is endless, and their distress is palpable. The researcher recognized this subset of women as those who are in need of understanding, compassion and most of all time, which in an emergency department is a most precious commodity.

Sadly, due to the relative medical stability of the majority of these women, they often have long wait times for evaluation of their bleeding and may perceive that nothing is being done to help them. This situation motivated policy change on the researchers unit which allowed triage nurses to order a specific panel of blood work for stable women with bleeding during early pregnancy while they are in the

waiting room. Although this seems to have greatly reduced the amount of time a woman spends waiting for blood work, she still must wait for ultrasonography which is required to make a definitive diagnosis of pregnancy loss.

Ultrasonography is typically the step in the evaluation of bleeding during pregnancy that women wait the longest for and yet it is considered the most fundamental and essential diagnostic tool used to determine the viability and placement of the pregnancy (Fox, Richardson, & Sharma, 2000; Griebel, Halvorsen, Golemon, & Day, 2005; Isoardi, 2009). Coppola and Coppola (2003) recommend early ultrasonography when it is "readily available" as it can provide "more timely diagnosis, enhance early intervention and patient counselling, and prevent infection" (p. 671). There is controversy in the use of early ultrasound evaluation, in that some physicians believe that ultrasonography can be delayed in hemodynamically stable women with few risk factors for ectopic pregnancy (Coppola & Coppola, 2003). In the setting in which the researcher is employed, ultrasounds are performed only during "day time" hours. Therefore, if a woman arrives to the emergency department during the evening or at night with bleeding during pregnancy, she has to wait overnight until the ultrasound department is open in the morning. Some women are sent home to wait for a call to return for an ultrasound, while other women remain in hospital overnight. There are exceptions to this, for instance, if a woman is hemodynamically unstable an ultrasound technician is called in to perform the ultrasound on an urgent basis. However, it is this researcher's experience that this is rare.

Emergency department are noted for providing unsatisfactory psychological support and care for women experiencing bleeding in pregnancy and pregnancy loss (Bacidore et al., 2009; Lee & Slade, 1996; Washbourne & Cox, 2002). Likewise, current literature acknowledges that many women experience significant grief reactions after miscarriage (Brier, 2008; Lee & Slade, 1996). However, there is a paucity of research on women's experience of "waiting" in the timeframe within which a pregnant woman discovers she is bleeding and awaits the fate of her pregnancy.

Drawing on personal experience and through conversation with other "waiting women" has revealed the following common themes; anxiety, rumination, frustration, and the willingness to accept any answer, even a negative one. At the heart of the matter is unknowing and uncertainty. Uncertainty has been described as a feeling or state that arises in a situation where a person cannot accurately predict outcomes and may be characterized by ambiguity, vagueness, inconsistency, unpredictability, unfamiliarity, or lack of information (Mishel, 1984). Uncertainty often results in stress due to an immobilization of anticipatory coping processes (Lazarus & Folkman, 1984). Oscillating between mutually exclusive outcomes and trying to prepare for either possible outcome is mentally exhausting. A pregnant woman experiencing bleeding can hardly prepare herself for mourning the loss of her anticipated child while simultaneously engaging in fantasies about her anticipated child. Literature supports this idea as "…coping strategies for anticipating an event's occurrence are often incompatible with

strategies needed to anticipate the event's non occurrence" (Lazarus & Folkman, 1984, p.91).

In order to further refine the research problem additional literature must be explored. Evidence specifically focused on the experience of pregnant women waiting in the emergency department with vaginal bleeding was not found so it will be necessary to move peripherally and gather existing information on waiting in other contexts. Moreover, although uncertainty itself is not identified in the research question, it is reasonable to assume that a pregnant woman with vaginal bleeding will experience at least some degree of uncertainty related to either her pregnancy outcome or her own health. Consequently, it will also be necessary to review current evidence where the existence of uncertainty in pregnancy is described.

Chapter Two

Review of the Literature

The chapter presents a review of selected literature as it pertains to bleeding in early pregnancy, uncertainty and waiting. Initially, the search strategy is described and then existing evidence on the incidence, evaluation, causes and management of bleeding in early pregnancy is outlined. The following section addresses the concept of uncertainty while the third focuses on literature surrounding uncertainty in pregnancy. Finally, the construct of waiting is examined, including literature describing the lived experiences of waiting.

Search Strategy

CINAHL, MEDLINE, and ProQuest Dissertations and theses databases as well as Google Scholar were searched using the following terms either alone or in combination: pregnant, pregnancy, early, pregnancy loss, vaginal bleeding, abortion, threatened, miscarriage, uncertainty, waiting, waiting room, emergency care, emergency department, emergency room. Furthermore, references and citations of relevant articles, theses and dissertations were inspected for additional pertinent articles.

Bleeding In Early Pregnancy

Prior to initiating a review of evidence on the experience of waiting among women with bleeding during pregnancy it is necessary to examine and describe bleeding during pregnancy, including its epidemiology, evaluation, causes and management. This is not meant to be an exhaustive review of the literature on the subject as that is not within the purview of this paper, but instead to provide background to the reader on bleeding during pregnancy.

Epidemiology.

Epidemiological research reveals that bleeding during pregnancy before 20 weeks of gestation affects as many as one in four pregnancies, with almost 50% of those advancing from threatened loss to complete loss of pregnancy (Everett, 1997; Hasan et al., 2009). In a two year prospective study, pregnant women (n=626) were evaluated for the presence of vaginal bleeding prior to 20 weeks gestation and then followed until the final outcome of pregnancy, that is pregnancy loss, pregnancy termination or delivery (Everett, 1997). Other

variables included parity, maternal age, diagnostic examinations, planned or unplanned pregnancy and previous pregnancy loss. The author concluded there is a need for further investigation of potential environmental influences on pregnancy loss. A limitation was that it was not readily apparent how the sample was recruited, nor which research method was implemented, although the author seems to suggest chart review. Moreover, this study was not published in the last decade and techniques such as ultrasonography and sensitivity of home pregnancy tests have since become more accurate. Therefore, these rates may underestimate the actual rate of pregnancy loss.

A 2009 study collected detailed data on first trimester bleeding from women in a community based cohort study and noted that of the 4510 participants, 27% reported vaginal bleeding or spotting and 11% suffered a pregnancy loss (Hasan et al., 2009). Although Hasan et al. (2009) observed an increased incidence of bleeding during pregnancy that is, 27% compared to 21% found by Everett (1997), both studies reported similar rates of pregnancy loss at 12% and 11% respectively.

Evaluation of bleeding during early pregnancy.

Obtaining a thorough history of the bleeding in early pregnancy is essential as it may provide an indication as to the cause of the bleeding. Women are asked to recount the onset of bleeding, consider what if anything was associated with the onset (intercourse, urinating etc.), to describe the amount, color and consistency of blood, including the presence of clots and whether or not discomfort or cramping is associated with the bleeding (Snell, 2009). Women

with bleeding during pregnancy may describe vaginal bleeding that is continuous or sporadic, bright red, pink or brown in color, and ranging from light spotting to heavy bleeding that includes the passage of tissue and/or clots (Coppola & Coppola, 2003). Moreover, lower back or abdominal cramping or pain may also be reported. Women are also asked about their previous medical history, including their obstetrical history such as timing of their last menstrual period, the number of times they have been pregnant and the outcomes of these pregnancies.

Several investigations are likely to be performed during an emergency room visit, which may include a speculum examination to allow for visualization of the cervix and vagina to characterize the bleeding, appreciate the integrity of the cervical os, and identify any trauma or abnormalities such as polyps or existence of infection (Coppola & Coppola, 2003; Deutchman, Tubay & Turok, 2009; Snell, 2009). Furthermore, a bimanual exam may be performed to determine the size and shape of the uterus as well as the presence of cervical tenderness on motion or adnexal masses (Deutchman et al., 2009; Snell, 2009). Blood work including quantitative β-Human Chorionic Gonadotropin (βhCG) levels, Rh status, complete blood count including differential, and blood typing will also be assessed (Snell, 2009). Finally, ultrasonography may be performed to rule out ectopic pregnancy and determine presence of fetal heart motion and fetal viability may be performed (Coppola & Coppola, 2003; Deutchman et al., 2009; Morin & Van den Hof, 2005). A clear algorithm for the process of managing a stable pregnant woman with bleeding in early pregnancy is attached as Appendix A (Coppola & Coppola, 2003).

Causes and management.

Vaginal bleeding in pregnancy has a variety of causes that includes obstetric factors, such as implantation bleeding, subchorionic hemorrhage, spontaneous pregnancy loss, ectopic pregnancy and molar pregnancy or non-obstetric factors, including post-coital bleeding, cervical lesions, uterine fibroids, infection and bleeding of an idiopathic nature (Coppola & Coppola, 2003; Griebel et al., 2005; Snell 2009). The initial objective for management of vaginal bleeding is supporting maternal health; women with significant blood loss or ectopic pregnancy may present in a shock state. The subsequent approach to bleeding will depend on the cause; with the most common abnormal finding in pregnant women with vaginal bleeding is spontaneous miscarriage (Snell, 2009). Management strategies of spontaneous miscarriage include surgical, expectant management, and medical management. Expectant management refers to allowing the body to expel the non-viable pregnancy on its own.

Even with access to early ultrasound and clinical examination, uncertainty exists. Health care providers cannot predict what will occur, especially in cases of threatened pregnancy loss where women are often told, “We don’t know what will happen” and “We have to just wait and see”. For some women a threatened pregnancy loss remains a reality until the bleeding resolves or even until delivery, which prolongs uncertainty. Moreover, the determination of pregnancy viability is fraught with uncertainty; absence of fetal heart tones on ultrasound may indicate pregnancy loss or a pregnancy too early to visualize (Coppola & Coppola, 2003, Morin & Van den Hof, 2005; Snell 2009). Likewise, a closed cervical os, while a

reassuring sign, does not rule out pregnancy loss. It seems practical to imagine that a woman in this situation may feel uncertain either about her pregnancy or her own health, and therefore evidence on the concept of uncertainty in pregnancy must be explored.

Uncertainty in Pregnancy

Does uncertainty in pregnancy exist?

In her doctoral dissertation Handley (2002) aimed to determine if uncertainty existed in pregnant women and whether uncertainty was distinct from the concepts of anxiety and depression. She also wanted to determine if levels of uncertainty were influenced by biological and demographic factors. In the initial phase of her research the author modified and assessed the psychometric properties of Mishel's *Uncertainty in Illness Scale* ([MUIS]; Mishel, 1981) for use in pregnant women. In the second phase, 128 primgravide women in their first trimester were purposively sampled from the offices of five obstetrical health care provider groups and asked to complete the modified MUIS scale, anxiety and depression subscales and demographic information.

Uncertainty in pregnancy exists, and it is a distinct construct from both anxiety and depression (Handley, 2002). Moreover, age, marital status, income and education level contributed to uncertainty scores with, younger, unmarried women who report lower levels of income and education demonstrating higher levels of uncertainty. Remarkably, Handley notes that pregnancy complications had no significant impact on uncertainty scores which may reflect reality or may be a function of insufficient sample size, with only approximately 10%, of women

experiencing pregnancy complications. In her recommendations, Handley suggests that more research is needed to understand the experience of women with complications during pregnancy and the impact this may have on uncertainty. Moreover, she proposes that qualitative inquiry could provide a richer, deeper understanding of uncertainty in pregnancy.

Uncertainty and stress in high-risk hospitalized pregnant women.

Clauson (1996) used a descriptive correlational design to understand how hospitalized antepartum women with high risk pregnancies perceive uncertainty and stress related to their condition and the relationship between this uncertainty and other factors. This was explored by investigating, the perceived level of uncertainty at two time points, the difference in perception between these time points, the difference in perception between primigravidas and multigravidas, and the correlation between uncertainty and several demographic and descriptive factors such as maternal age, gestational age and length of stay (Clauson, 1996). Participants (n=58) were recruited using convenience sampling from high-risk antepartum units in a large Canadian hospital; they were given two identical copies of a scale designed to measure perceived uncertainty, and asked to complete one 48 hours after admission and the other immediately prior to discharge from the hospital.

Data analysis indicated that at Time 1, forty-eight hours after admission, 86% of women scored low or moderate on uncertainty while 14% reported high uncertainty scores (Clauson, 1996). However, at time of discharge uncertainty scores were significantly lower, with only 9% indicating high uncertainty. There

was a positive correlation between stress and uncertainty scores at both Time 1 and Time 2 (r=.73 at Time 1; r=.71 at Time 2), and between uncertainty and length of stay (r=.23) (Clauson, 1996, p.317). Moreover, there was an inverse correlation (r= -.27) between gestational age and uncertainty scores. The author explains this inverse correlation by hypothesizing that as gestational age increases, fetal risk decreases and therefore so does uncertainty. This finding is of particular interest, in that if it holds true for a subset of women who experience bleeding in early pregnancy, they could be at risk for the highest levels of uncertainty. Recommendations for further research included comparing uncertainty scores in high and low risk pregnancies, examining uncertainty scores of the partners of women with high-risk pregnancies and determining the impact of uncertainty on children and other family members. Limitations addressed by the author included the small sample size and lack of psychometric testing of their study instrument.

Sample selection and participant demographics were clearly detailed and inclusion and exclusion criteria were well defined. The purpose of the study and the questions the author sought to answer were evident and clearly presented. While the literature review was inclusive, incongruence existed between the purpose statement and the research questions, as the research questions exclude any mention of perceived stress in this population. Although this study was quantitative, the author also includes a quotation that was written on the bottom of one of the questionnaires. While the research method was well chosen for the type of question it aimed to answer, a mixed method study that included qualitative

inquiry might have provided more useful insight into how women experience uncertainty. This article is a summary of the author's dissertation, and it is possible that in condensing the material for publication some pertinent information was excluded. The findings of this study are likely not applicable to early pregnancy as pregnant women whose gestational ages were less than 20 weeks were specifically excluded from the study. It is also plausible that being in hospital has an effect on uncertainty scores and that women in early pregnancy would have higher uncertainty scores, as they are rarely hospitalized unless they require intervention.

Uncertainty, social support and prenatal coping.

A convenience sample of high risk pregnant women (n=105) participated in a cross-sectional, descriptive, correlational study aimed at determining the relationships between uncertainty, social support and prenatal coping strategies (Giurgescu, Penckofer, Maurer, & Bryant, 2006). Correlational analysis revealed that higher levels of uncertainty were correlated with less social support (r= -.45), poorer psychological well being (r=-.48), and more use of avoidance as a coping strategy (r=.43) (Giurgescu et al., 2006, p. 356). Fascinatingly, in contrast to other studies no correlation was found between uncertainty score and gestational age. Moreover, the high-risk pregnant women in this study reported low uncertainty scores, which again is in contrast with the results of other studies (Gray, 2001; Gupton, Heaman, & Ashcroft, 1997).

Recommendations for future research were meager, and included suggestions for evaluating distress and well-being simultaneously, as well as

research aimed at developing interventions to reduce uncertainty in high-risk pregnant women. While this would seem like a desirable outcome, it does not seem to flow from the study findings which indicated that the women in this study had low levels of uncertainty. Study limitations include small sample size and limited applicability of these findings to low-risk pregnancies. The authors also report that a correlational design was, by nature, a limitation as it did not allow for manipulation of the independent variable or the ability to randomly assign participants to intervention groups; this does not seem relevant in this case as the purpose of the study was not to evaluate an intervention. The authors offered a theoretical basis in which to frame their concepts. Moreover, concepts were well defined and supported with existing evidence. Inclusion and exclusion criteria for sample selection were stated and rationale was provided. Data collection instruments were outlined and their validity was supported; moreover, results were logically and clearly presented. The discussion section included evidence from other studies that both confirmed and refuted the author's findings. This study could potentially be replicated in a target population of women with bleeding in early pregnancy, however due to gestational age requirement the findings are not representative of women in early pregnancy.

Experiences of Waiting

Waiting is an ambiguous experience and is and will remain so due to the vague and indistinct language used to describe it (van Manen, 2002). Waiting is so familiar and universal that we feel we know its meaning, yet would have difficulty explaining this experience (Fujita, 2002). Two qualities characterize

waiting; “what is waited for”, the “objective” aspect of waiting and “how we wait”, the subjective aspect of waiting (Fujita, 2002, p. 128). Fujita (2002) offers that there are three worlds of the objective aspect of waiting, which include, the mechanical world, the natural world and the world of becoming. The mechanical world typifies waiting as a means to an end where waiting is unproductive or meaningless; this includes waiting for an elevator or a coffee from a vending machine. Waiting in the natural world is waiting for the sunrise or flowers to bloom and is differentiated by “powerlessness of the self and by trust in external rhythms” (Fujita, 2002, p. 131). Waiting in the world of becoming is the most elusive and is characterized by a ‘what is waited for’ that is vague and undefined (Fujita, 2002). Interestingly, Fujita places the example of a pregnant woman waiting for a baby to be born in the category of waiting in the natural world but affords that with advances in technology, waiting for a baby to be born could also be described as waiting in the mechanical world. Therefore, if the boundaries between these waiting worlds are not clear, nor mutually exclusive then being pregnant, especially while experiencing bleeding could for some women be waiting in the world of becoming. The subjective aspect of waiting must also be considered. The perception of waiting is equal if not more important than the objective measure that is, the time waited. One minute may seem fleeting or may feel like an eternity and the perception of this waiting can be influenced by many factors which will be further elaborated on.

Waiting in the intensive care waiting room.

The essence of the experience of waiting within the context of waiting for a loved one in the critical care unit was explored using a phenomenological-hermeneutic research method (Bournes & Mitchell, 2002). The research question used to guide this inquiry was, "What is the structure of the lived experiences of waiting" (Bournes & Mitchell, 2002, p. 58). The participants (n=12) were family members of adults in a critical care unit in a large Canadian hospital. Congruent with the choice of research method, only one question was asked during participant interviews, "Please tell me about your experience of waiting" (p. 60). Data gathering and concurrent analysis revealed three core concepts that are labeled as: a) vigilant attentiveness, b) ambiguous turbulent lull, and c) contentment with uplifting engagements. Vigilant attentiveness was the term used to describe participants' feelings of persistent watchfulness, such as experiencing "a sense of urgency to get back [to their loved one]" and constantly "thinking about it" (p. 62). Ambiguous turbulent lull was characterized by feelings of "turmoil that they had to endure while living with the not knowing what would happen" (p.62). Subsumed within this concept were participant expressions of "feeling like their lives were on hold" (p. 62). Finally, contentment with uplifting engagements was illustrated by exemplars such as "feeling better" when they could "share their experiences" or "do little things" (p. 63).

The authors suggest the need to further identify lived experiences of waiting in other contexts to gain greater insights into this phenomenon. With respect to practice, one concrete recommendation that surfaced from this

philosophical discourse is that nurses need to have a more in depth understanding of the experience of waiting, specifically within the frame of loved ones conforming or not conforming to hospital rules, especially those that keep them separated from their families. The choice of research method was appropriately selected and apparent in the choice of research question. The authors adequately provided the basis for the Parse theory of human becoming. The significance of the problem was clearly articulated and key concepts were well supported with excerpts from participant interviews. Recommendations for practice were offered and well outlined.

While this study illustrates the essence of waiting for a loved one in critical care the findings cannot be transferable to the context of bleeding during early pregnancy without further investigation. This may be inherent in the "type" of waiting, that is, the lived experience of waiting for a loved one may differ from the experience of waiting for oneself or waiting for something less concrete.

Kutash and Northrup (2007) also sought to understand family members' perspectives of the waiting room and the experience of waiting while their loved one was admitted to an intensive care unit. However, in contrast to the previous study, a constant comparative research method of semi-structured interviews was used. A convenience sample of women (n=6) who had a relative admitted to the neuroscience intensive care unit of a single hospital were interviewed with an interview guide containing questions such as, "What is it like to wait, what is the most difficult part of waiting, and what would make waiting easier for you?" (Kutash & Northrup, 2007, p. 385). Six categories were identified from these

interviews, including; close proximity, caring staff, need for a comfortable environment, emotional support, roller coaster of emotions and information. The authors reported that they collected and analyzed data simultaneously and that they continued interviewing until no new information was obtained. With the assumption that the authors meant this statement in relation to the number of interviews they conducted as opposed to the length of each individual interview then it would seem reasonable despite small sample size that data saturation was achieved. The authors did explicitly state what was already known on the topic and what their research contributed. Unfortunately, the description of research methodology and the rationale for choosing it was limited. Suggestions for future research were provided including, determining how cultural and spiritual beliefs may influence waiting, and devising interventions to ease the waiting period. Again, these findings like those of Bournes and Mitchell (2002) illuminate the experience of waiting for a loved one and as such it is not clear whether the conclusions of this study would hold true in the context of bleeding during early pregnancy.

Interestingly, these interviews did reveal a more concrete aspect of waiting which was the category named “comfortable environment. Comfortable environment referred to the physical condition and layout of the waiting room including the comfort of the furniture and having clean blankets and water. It seems reasonable to consider that the physical waiting room environment is a factor influencing the experience of waiting for both these participants and women who are bleeding during pregnancy.

Waiting in the outpatient setting.

Moving on from the prior studies to a distinct cohort, interview data from cancer patients (n=355) in an outpatient oncology clinic waiting room were analyzed (Catania et al., 2011). The goal of this study was to identify moods and fears of cancer patients, determine whether their physician perceptions were congruent with that of patients and develop "concrete suggestions for an anthropocentric transformation of waiting itself" (Catania et al, 2011, p. 388). Participants (n=355) were asked to respond to a 15 item questionnaire that related to evaluation of the waiting period, perception of the length of waiting and waiting room, suggestions on how to make waiting more constructive, and suggestions on how to structurally change the waiting. More than half the respondents indicated they found waiting long or too long, while 43% indicated waiting was acceptable or short. The questionnaire asked participants to choose whether they found waiting to be; (a) distressing, (b) boring, (c) useless, or (d) physiological [sic] distressing (Catania et al., 2011, p. 389). Fifty percent answered that they found waiting to be boring, while 43% found it distressing or physiological[*sic*] distressing (p. 390). Firstly it is not apparent what the distinction between distressing and physiological[*sic*] distressing is. Additionally, the choice of these particular words could have influenced the respondents by promoting a negative association of waiting and thereby impacting their other responses to the study. Neutral and positive responses should have been included as choices, such as 'neither good nor bad' or 'leisurely'. The majority of respondents indicated they would like to have the option to leave the waiting

room and be called back when it was their turn. When the respondents were asked what they would like to change about the waiting room the most common response, that is 40% of wanted more comfortable chairs or surroundings. Of the 355 patients, recruited, the authors report that all 355 questionnaires were returned and completed. However there is some confusion as later in the paper the authors indicate that 301 subjects answered the questionnaire, it is not clear where the discrepancy exists (Catania et al., 2011, p. 391). Utilizing a self administered questionnaire approach the authors were able to garner the opinions of waiting of a reasonable non-probability sample (n=355), however richer data would likely have been obtained from the inclusion of more choices in the multiple choice questions or preferably from the use of more open-ended questions. The inclusion of the two open-ended questions did allow for some variation in response; regrettably, the authors did not describe how the open-ended questions were evaluated or characterized. Moreover, this paper does not appear to meet its goal of the anthropocentric transformation of waiting itself nor is there mention of comparing participant responses to the perceptions of their physicians. While this study does provide some valuable insight into how patients would aim to improve their waiting process, such as making the furniture more comfortable or providing the freedom to leave the waiting room, it adds little to describing the experience of waiting. Once more because this research was conducted with cancer patients in an outpatient clinic, the findings may not be generalized to women who are pregnant and bleeding and waiting in an emergency department setting. Noteworthy is that more than 70% of the patients in this study indicated that the

emotional cost of waiting was little or none. This is perhaps related to the construct of uncertainty in that the respondents in this cohort were experiencing less uncertainty at that particular time as they knew the "what" of what they are waiting for, their appointment, and therefore experienced less anxiety.

Waiting among women hospitalized in the antepartum period.

In a phenomenological study based on Parse's theory of Human Becoming, the lived experience of waiting among hospitalized antepartum women was explored (Thornburg, 2002). The research question was, "What is waiting like for women who must be hospitalized during their pregnancies" (Thornburg, 2002, p. 246). Participants (n=14) were purposively chosen from women hospitalized on an antenatal maternity unit. Paralleling Bournes and Mitchell (2002) only the following question was asked during the interview, "Tell me what your experience of waiting is like" (Thornburg, 2002, p. 245). Four key themes were identified, a) enduring vigil, b) burdening toil, c) engaging-disengaging with close others and, d) cherishing the can-be. Recommendations for future research were not reported. Limitations included removing four interviews from analysis "due to lack of sufficient transcribable information" as well as not providing demographic information such as why the women were hospitalized (Thornburg, 2002, p. 246).

Key themes were briefly illustrated with exemplars from the participants; however the essence of the participant experiences might have been better conveyed with more elaborate and in-depth descriptions. The description of participant selection and demographics were not clearly defined, for instance

gestational age was not provided. In addition, the article did not fully explain the basis of Parse's theory, so the reader required outside knowledge to see its applicability in this context. Conversely, data analysis methods were comprehensively and richly described. Criteria for rigor were met and examples were provided for how this was achieved. The major limitation for transferability of the study findings to early pregnancy is that the author indicates that value exists in waiting for the women in this study, as the agony of waiting is of unseen value for the importance of the health of their babies. Within the context of early pregnancy loss, or threatened loss, there may be no inherent value in waiting, since patiently waiting is not likely to change the outcome. However, it is not possible to say at this point whether or not women in early pregnancy perceive this to be true.

Waiting for diagnosis after abnormal mammogram.

The experience of waiting for definitive diagnosis following an abnormal screening mammogram was explored (Thorne, Harris, Hislop & Vestrup, 1999). Focus group interviews were conducted where women (n=33) were first asked to tell their own story about their abnormal mammogram and the ensuing diagnostic process and then trigger questions were used as a prompt to identify both effective and ineffective elements of their experience. Theoretical sampling according to age and diagnosis was used to select potential participants from a breast screening program with the function being a heterogeneous mix of women in each focus group; including women older and younger than 50 and women who had been subsequently diagnosed and not diagnosed with cancer.

Data analysis was conducted via inductive analytic strategies and provides elaboration of this process. Vigorous attempts to maintain rigor, including cross-referencing the data, and assessing the fit of the data with existing sources were made. Despite the range in personal experience several issues evolved from the focus groups including, access to appropriate and accurate information, removing bureaucratic barriers, and the effect of health care communication on the waiting experience. Many women described feeling dehumanized by their health care providers during the diagnostic process and how this led to a significant source of distress. Furthermore, an emerging theme was that health care system barriers and the lack of effective coordination created additional complications to their waiting process. Although not explicitly stated as recommendations, the findings proffer that health care providers need to be more attuned to the women in this waiting process, and to focus on reducing delays associated with the diagnostic process. The length of time elapsed from diagnosis to the timing of the focus group was not reported, which may have had some impact on the memory of the experiences.

This study is particularly pertinent as the experiences of both women who were eventually diagnosed and also those not diagnosed with cancer were examined. And notably, the findings revealed that waiting for diagnosis evoked powerful emotions for women irrespective of whether they were eventually diagnosed with cancer. These findings may have some transferability to the experience of waiting in women that had bleeding during pregnancy which progressed to pregnancy loss and those that did not.

A coping intervention for waiting.

A double-blind experimental design was used to determine which coping intervention would be most effective for women awaiting pregnancy test after IVF embryo transfer (Lancastle & Boivin, 2008). Women (n=55) were assigned to groups and asked to read a card that contained either 10 positive reappraisal coping (PRCI) statements, or ten positive mood (PMI) statements, twice daily for the time period between embryo transfer and taking a pregnancy test (Lancastle & Boivin, 2008). PRCI statements included items such as, "during this experience I will focus on the benefits and not just the difficulties" or "find something good in what is happening" (p. 2301). The PMI included items such as "during this experience I feel that "I am a great person, or "life is great" (p. 2301). Statistical analysis supported a hypothesis that the PRCI made participants feel more positive and preserve coping, when compared to the PMI. Moreover, there was a significant difference in acceptability to participants of the PRCI who indicated they would use the intervention again and would it recommend to others. Future research is proposed in the area of evaluating the use of PRCI and routine care during the waiting period.

Sufficient literature was provided as rational to pursue their proposal. The use of a double blind experimental method is valid; however hypotheses were not explicitly stated. The inclusion of graphs facilitates the understanding of the large amount of data and the authors indicate efforts to control other variables. Although the PRCI has merit, it is difficult to determine the extent of the benefit as there is no baseline with which to compare. It would have been more effective

if a third group was included as a control to determine baseline coping. It is possible that these coping interventions can be transferred to other types of waiting, as suggested by the authors and the participants. On the other hand, this intervention may have little benefit to women with vaginal bleeding, or may worsen their emotional discomfort.

Gaps in Literature

Several gaps in what is known about the experience of waiting when vaginal bleeding occurs in early pregnancy were identified. The review of literature did not produce any articles pertaining to the experience of vaginal bleeding in pregnancy prior to diagnosis of miscarriage; nearly all of the existing literature that was found surrounding early pregnancy deals with pregnancy loss. While the existence of uncertainty in pregnancy has been established (Handley, 2002) and investigated with respect to its relationship to variables such as, social support, maternal age, gravidity, education level, information provision (Ashcroft, 1995; Clauson, 1996; Giurgescu et al., 2006; Hui Choi et al., 2012) it has not been evaluated in the context of bleeding during early pregnancy. The experience of waiting in certain circumstances has been described, including waiting in a critical care waiting room (Bournes & Mitchell, 2002; Kutash & Northrup, 2007), waiting in the outpatient setting (Catania et al., 2011), waiting among women hospitalized antepartum women (Thornburg, 2002) and waiting for outcome of IVF embryo transfer (Lancastle & Boivin, 2008). Additional literature exists on the experience of waiting in the context of waiting for organ transplant (Baker & McWilliam, 2003; MacDonald, 2006; Naef & Bournes, 2009), waiting

for coronary artery bypass (Jónsdóttir & Baldursdóttir, 1998) and waiting while in long-term care (Mitchell et al., 2005). While these articles may provide insight into the human experience of waiting, none describe waiting in the context of bleeding during early pregnancy. In fact, most studies that did include pregnant women specifically excluded women whose gestational age was less than 20 weeks. These gaps in conjunction with the prevalence of bleeding in early pregnancy lend credence to the need to examine these concepts in early pregnancy.

Purpose

This project addresses the research question: How do women with bleeding in early pregnancy describe their experience of waiting in the emergency department? The overarching goals are to explore and describe women's experience of waiting in the context of bleeding in early pregnancy and to improve women's satisfaction with care by strengthening nursing knowledge and skills needed to care for them.

For the purposes of this study, 'early pregnancy' will refer to a pregnancy that is confirmed either by urine testing or by quantitative βhCG serum testing and is less than 20 weeks gestation either by dates or by ultrasound. 'Bleeding in early pregnancy' is any vaginal bleeding which could potentially jeopardize the pregnancy. The term 'spontaneous abortion' will not be used; instead pregnancy loss or miscarriage will be employed to denote any loss of pregnancy prior to 20 weeks that is not associated with pregnancy termination. 'Pregnancy termination' is used in place of the term 'therapeutic abortion'.

Chapter Three

Methods

This section will outline the research design, the study sample, data collection procedure, instrument, data analysis, strategies to address and maintain rigor, and ethical considerations.

Research Design

An interpretive descriptive design was used to explore the research question: How do women with bleeding in early pregnancy describe their experience of waiting in the emergency department? This method follows the traditions of qualitative inquiry into "human health and illness experiences for the purpose of developing nursing knowledge" (Thorne, Kirkham, and MacDonald-Emes, 1997, p.172). Interpretive description serves to contribute "directly to our understanding of how people experience their health and illness and what nursing can do to make a difference" (Thorne et al., 1997, p.173). Nursing, unlike basic sciences is a practical science, and therefore research is not merely theoretical. Hence, interpretive description was born out of the recognition that "...qualitative approaches derived from other disciplines have not always met the unique demands of nurse researchers" (Thorne et al., 1997, p. 169). Furthermore, this methodological approach, "acknowledges the constructed and contextual nature of much of the health–illness experience, yet also allows for shared realities' (Thorne et al., 1997, p. 172). An understanding of the phenomenon is achieved by deconstructing the meaning of a phenomenon and then reconstructing the new knowledge about the phenomenon in the context of evolving knowledge (Morse,

1994; Thorne, 2000). The goal of interpretive description is to develop a description that identifies commonalities and patterns believed to characterize the phenomenon and use this to inform clinical understanding (Thorne, Reimer, O'Flynn-Magee, 2004, p. 4).

Interpretive description is an appropriate method exploring the experience of waiting among pregnant women with vaginal bleeding due to the scarcity of evidence found about this topic. Furthermore, the wording of the research question, specifically the use of the words "describe" and "experience", direct the reader to consider this type of qualitative methodology.

Study Sample

Six participants were recruited between February 2012 and April of 2013. It was intended that participants would initially be selected via convenience sampling with sampling becoming more purposive as specific deficits in what needs to be known were recognized. The researcher endeavored to select participants who displayed the phenomenon of interest that is, bleeding in pregnant women and then as new information surfaced the researcher aimed for maximal variation on the themes that emerged (Thorne et al., 1997). For instance, the researcher reasoned that the experience of a pregnant woman with bleeding who progressed to pregnancy loss may differ from one who does not; therefore, fully exploring the experience of vaginal bleeding in pregnancy would require speaking with women who had experienced pregnancy loss, and those maintained a viable pregnancy. Additionally, it was reasoned that primigravid women may experience their situation differently than those that are multigravid, and again it

would be important to include both types of women. Due to some challenges with recruitment, which will be expanded on below, the ambition of progressing to choosing participants purposively did not prove achievable. Despite this, of the women who participated there was a mix for which their vaginal bleeding signaled the end of their pregnancy and those who remained pregnant. There was also diversity with respect to obstetrical history, including gravidity.

Determining the size of sample needed in a qualitative study is complicated and cannot be achieved with a calculation or set *a priori*. Morse (2000) argues that the " participants required in a study is one area in which it is clear that too many factors are involved and conditions of each study vary too greatly to produce tight recommendations" (p. 5). Moreover, she summarizes several factors that impact the sample size, such as scope of the study, nature of the topic, quality of the data and study design (Morse, 2000). Of these factors the quality of the data surfaces as the most significant factor, as the greater the amount of useable data generated, the fewer number of participants needed. Study design is also noteworthy as fewer participants are needed when unstructured interviews are employed or when interviewing the same participants multiple times (Morse, 2000). Therefore, a specific sample size was not set and instead was determined when data saturation had been achieved, which is when "no new themes or essences have emerged from the participants" (Streubert Speziale & Carpenter, 2007, p.95). Whether or not saturation of qualitative data is indeed a myth, the researcher continued with data collection and analysis until it appeared that no new themes were emerging and it was possible to learn something about

the phenomenon at that particular time with that particular group of participants (Mayan, 2009; Streubert Speziale & Carpenter, 2007).

Eligibility criteria.

In order to fully explore the experience of waiting among women with vaginal bleeding in pregnancy, it would be necessary to talk to every woman who has ever had this experience; however this is neither possible nor feasible. Therefore, the accessible population will include women who are available to be interviewed and meet eligibility criteria. Individuals eligible to participate will be women who present to an emergency room in Edmonton, Alberta for evaluation of vaginal bleeding during pregnancy who are at least 18 years old. Hospital policy dictates that pregnant women over 20 weeks gestation are assessed in the labour and delivery unit, while pregnant women less than 20 weeks gestation are assessed in the emergency department. For this reason most women presenting to an emergency department for vaginal bleeding will be less than 20 completed weeks of gestation. However, pregnant women of any gestation age would not be excluded from participating. Moreover, if women whose primary language of communication was not English expressed interest in participating in the project, the researcher would have retained a translator to explain participation and obtain consent.

It was proposed that in order to allow for the richest data collection no more than sixteen weeks from the onset of bleeding should have elapsed prior to the interview. However, this criterion would have eliminated three of the women that expressed interest in participating in this study. The researcher reasoned that

bleeding during pregnancy would be a significant enough event for women that despite the passage of time they would be able to recount the essence of what they were feeling. Most importantly, the researcher believes strongly they each of these women provided important insights. In summary, no absolute exclusion criteria were set so as to take advantage of unanticipated opportunities should they arise.

Data Collection

Alberta Health Services operational approval via NACTRAC was granted to recruit participants from the emergency department at the University of Alberta in January of 2012. Posters requesting participation and outlining the purpose of the study were placed in strategic locations throughout the emergency department and waiting room. A copy of the poster is included as Appendix B. Furthermore, a memo was circulated to nursing staff advising them of the study, explaining its purpose and outlining their role in recruitment. The memo is included as Appendix C. Data collection was designed to minimize any involvement of site nursing staff and site nursing staff were not required to have any more than a basic knowledge about the study, nor did they assist in enrolling participants in the study. This was in part to enhance cooperation of the staff but to also protect patients from any concerns that choosing non- participation may impact their care. If nursing staff were so inclined they could direct pregnant women with bleeding to the posters or they could provide women with an invitation that briefly described the study and included both phone and email contact information for the researcher to participate. This invitation to participate is included as Appendix D.

Due to lack of sufficient interest in the study after several months of recruitment efforts it became apparent that it would be difficult to obtain an adequate number of participants within a reasonable time period from only one site. Therefore, site approval was sought and granted at the Grey Nuns Emergency Department in March of 2012 and posters were hung and a memo circulated to staff (Refer to Appendices B & C). Regrettably, there remained a lack of interest in the study. Moreover, in April of 2012 the researcher was required to withdraw from actively seeking participants due to medical concerns. When the researcher was again able to seek out participants it was decided in consultation with Dr. Beverley O'Brien, the researcher's thesis supervisor that additional participants could be sought via advertisement in the social media forums. Therefore, invitations to participate were posted to several Facebook groups for local moms as well as via word of mouth. This yielded three more participants, all of whom were not in the originally proposed 16 week post bleeding time frame. Moreover, one of the participants had not visited the emergency department and had instead sought assessment by her family physician. However, as reasoned earlier the researcher believed they would still have something significant to add to experience of waiting while bleeding and thus these women were included.

Once women indicated their interest in participating in the study either via phone or email, the researcher forwarded a copy of the invitation to participate as well as the consent form via email. (Refer to Appendices D & E). Participants were asked only to read the consent and make note of any questions they may

have had. Finally, if participants indicated they wanted to proceed, a time and location for the interview was arranged.

Instrument.

Unstructured interviews with the researcher are the most suitable instruments to explore this research question as those who have had the experience we are seeking to understand are the best source of knowledge about this experience (Thorne et al., 1997). Unstructured interviews and open ended questions are common in qualitative research as they provide opportunity for participants to fully describe their experience and allow for greater flexibility and freedom in the responses they provide (Streubert Speziale & Carpenter, 2007). Moreover, unstructured interviews are guided by participants' responses and allow participants to lead the discussion while the researcher functions as a facilitator in the expression of participant experiences (Streubert Speziale & Carpenter, 2007).

Interviews took place in a safe, private, environment at a mutually convenient time for both participant and researcher. Interview locations varied with some taking place in a meeting room at the University of Alberta, some in participant's homes and one via telephone. All of the interviews were conducted in English. After introductions were made, the meeting opened with a brief description of the purpose of the study, a reminder that the participant was free to withdraw at any time and the opportunity to ask any questions or clarify any information was provided. Next, demographic information such as age, level of education, occupation, marital status and obstetrical history was collected. This

demographic questionnaire is included as Appendix F. Subsequently, the interview continued with the "grand tour question" and was then followed by a few other broad questions (Mayan, 2009, p. 71). The opening or "grand tour" question of the interview was, "Tell me about when you first discovered you were bleeding, what was the experience of waiting like for you"? If required, interview probes were used to encourage discussion with the participant. An interview guide is included as Appendix G.

There was no time limit set on the duration of the interview, and it continued until the participant indicated that she had no more to add to the conversation. Interviews were digitally recorded with permission from the participant. Notes were taken during the interview with the intention of reminding the interviewer to cue the participant in clarifying or elaborating on something the participant may have said that was significant. Personal reflections were recorded after the interview so as to capture the impressions of any subtle nuances such as body language or emotion. At the conclusion of the interview participants were provided with a card with contact information for counseling and mental health services. Additionally, a follow-up telephone call was made to participants 24 to 48 hours post interview if women were agreeable in order to ascertain the need for any referrals.

Interviewer.

As mentioned earlier, the interviewer was employed in a busy emergency department of a hospital with a large maternity center; and the number of women experiencing vaginal bleeding during pregnancy often seems endless. The moral

dissonance created in this environment reflects the need for change to improve the care of these women, and the first step in this process is to understand their experiences. The researcher experienced this phenomena first hand, further enhancing her interest in this area. Although the researcher holds certain beliefs about women with vaginal bleeding during pregnancy, such as believing they would feel uncertain or distressed, she is open to many potential affects. For instance, if a woman indicated she was relieved with the possibility of pregnancy loss the researcher understands the need to remain impartial as she can appreciate the complex interplay of emotions when a woman becomes pregnant. Moreover, the researcher accepts a woman's right to control her reproductive life.

Data Analysis

Data analysis occurred concurrently with data collection in a "systematic pattern of data collection-analysis-collection-analysis" (Morse, 1999, p.573). For instance, common concepts began to appear in the interviews, and this provided additional direction for the researcher in subsequent interviews. Transcripts were read several times, initially for an overall sense of the experience the participant was describing and then for content analysis. The purpose of this was for the researcher to repeatedly immerse herself in the data and "come to know individual cases intimately" (Thorne et al., 1997. p.175). Moreover, digital recordings of the interview were listened to and compared to written transcripts both to maintain rigor but also to remind the researcher of any emotional cues or overall tone that may have existed at the time of interview. During this process the researcher reflected on, "what is happening here?" and "what am I learning about this?"

(Thorne et al., 1997, p.174). Repeated immersion is imperative ahead of attempting categorization and extraction of themes and functions to allow processes such as synthesizing, theorizing, and recontextualizing (Morse, 1994; Thorne et al., 1997).

Synthesizing is considered the sifting phase of analysis and involves merging of the cases or stories to describe typical patterns or behaviors in addition to separating the significant from the insignificant (Morse, 1994). In this phase, the researcher systematically scanned each transcript and with the use of Microsoft Word sorted significant concepts into separate word files. After each transcript was complete the Word files were organized and separate files were merged with files that were similar. Finally, each Word file was perused for its content and if it was noted that several participants had content relevant to that concept the transcripts of the other participants were reexamined to ensure that they had not mentioned something similar that was missed.

The sorting phase of analysis is termed theorizing and involves "systematic selection and fitting of alternate models to the data" (Morse, 1994, p.33). More explicitly, the researcher builds alternate explanations of the phenomenon and compares them to the data until the best fit become visible (Morse, 1994). The researcher took note of similarities and differences between the women and reflected on possible explanatory factors as well as interpretations provided by participants. Lastly, is process of recontextualizing which Morse (1994) considers as the "real power or qualitative research" (p.34). Recontextualizing is described as developing emerging theory so that it is

applicable to other settings by linking the new findings with established theory to allow for discipline advances (Morse, 1994). Finally, the results were assessed for how well it fit within current existing literature.

The goal of interpretive description is a "coherent conceptual description that taps thematic patterns and commonalities believed to characterize the phenomenon" (Thorne, Reimer, O'Flynn-Magee, 2004, p. 4). In particular, the aim was to create a description of how women with vaginal bleeding during early pregnancy experience waiting and how we can use this description to shape and inform clinical understanding.

Rigor

Interviews were transcribed with the aid of a paid transcriber who signed a confidentiality agreement. It was anticipated that when interviews were nearing saturation, additional interviews would be conducted with the intent of sharing current themes and conceptualizations with participants to determine if the data resonates with their experiences; however due to lack of volunteers wanting to participate in the study this was not practical. This would have enhanced credibility of the data by determining that the findings accurately represent participant descriptions of the experience of waiting with vaginal bleeding during early pregnancy. A book of analytic decisions, codes and categories was kept; moreover, sufficient information will be included in any written reports to allow the reader "to follow the analytic reasoning process and to judge the degree to which the analysis is grounded within the data" (Thorne et al., 1997, p.175). The

researcher will provide thick and rich descriptions of the data to provide an adequate description of the phenomena.

Ethical Considerations

The proposal for this research was approved by the University of Alberta Health Research Ethics Board Panel B. As indicated in the data collection procedure, women were not approached by the researcher at any point which should have mitigated any concerns of obligation to participate. Potential risks and benefits of participation in the study were explained and participants were assured that their decision about whether or not to participate would not impact their medical care. Participants were asked to provide written consent if they agreed to participate as well as oral consent to allow digital audio recording of their interview. Moreover, women were reassured that participation in the study would remain confidential and that any published information would not contain any identifying characteristics; no one other than the investigator would know of their participation unless they choose to disclose it to others. Any published information will not contain any identifying characteristics and no names will be attached to any direct quotes. Any information collected such as demographic sheets, audiotapes, or transcribed material will be kept in a locked cabinet for a minimum of five years and then destroyed. In addition, any persons peripherally involved with the project, such as transcribers were asked to sign a confidentiality agreement. Furthermore, participants were assured that they would be free to withdraw from the study at any time except after data analysis was underway as it would be difficult remove. Fortunately, it was not necessary; however the

researcher was prepared to discontinue the interview if participants were unduly distressed. Finally as indicated earlier, at the conclusion of the interview women were provided with a card containing contact information for counseling and mental health services and if they were agreeable, a follow-up telephone call was made 24 to 48 hours post interview to ascertain the need for any referrals.

Chapter Four

Presentation of Findings

This section will outline the demographic information of the participants and describe the concepts that emerged from talking with women about their experience of waiting while bleeding during early pregnancy.

Demographic Characteristics of Participants

A total of six women participated in the study. Women ranged in age from 29 to 43, with an average age of 34.6. All of the women were married and had at least a university degree. Obstetrical history varied with the highest gravidity being four and the lowest one. At the time of interview all but one participant had at least one live child. Two women had experienced previous pregnancy loss prior to bleeding in their index pregnancy. All of the women experienced bleeding in pregnancy, with bleeding occurring between five and 14 weeks of gestational age. Five women were assessed in the emergency department and one woman sought assessment by her family physician. Three women progressed to pregnancy loss, two delivered healthy live infants and one woman was still pregnant at the time of interview. Only one woman was able to have an ultrasound exam at the time of

initial presentation, the remaining five women were required to wait until at least the next day.

Uncertainty

Uncertainty was a prevailing theme in women's descriptions of their experiences of bleeding during pregnancy. Women expressed uncertainty when the bleeding first began, including, what they were expected to do about it, what it could mean and what to expect. When women presented for evaluation of their bleeding they remained uncertain with respect to the process of how they would be evaluated during their visit; for example, how long they could expect to wait before assessment, the priority system of the waiting room, such as who would be cared for first, and what the evaluation of their bleeding would entail. Furthermore, most of the women were discharged from the hospital to await an ultrasound examination and the lack of information and resolution of their chief concern at that time fuelled their uncertainty. Finally, for some women the ultrasound represented the peak of uncertainty. Although they had an answer about the fate of their pregnancy, most were sent home with no instructions about what to anticipate. For other women the ultrasound was not the final step and they remained uncertain about the fate of their pregnancy until successful delivery of their infant.

Where should I go for answers?

Women described feeling uncertainty from the moment their bleeding started. Their initial questions were related to what they should do about the bleeding, such as if they should seek medical attention and if so where they

should go. One woman offered, "I started spotting and quickly called all my friends, like, "What do I do?!" Another woman mentioned,

> I started having cramps and the bleeding pretty much started after the cramping started and I'd heard previously that you shouldn't go to the emergency room, so I wasn't planning on doing that, so I just was going to call the Capital Health Hotline and see what they had to say.

Yet another participant recounted:

> I went to the washroom and noticed that I had some spotting. So at first I was like, okay, you know, I've heard of this happening, not a big deal, kept pretty calm about it. Told my husband and then I decided to look things up on the internet, which was a mistake because it's all bad stories. So then I started to panic and my husband, because I was in tears, was like, "Let's just go to the emergency room, then you can feel better, we'll make sure everything's okay".

What does the bleeding mean?

Participants expressed disconcertion that even being assessed by a doctor after waiting in the waiting room did not provide answers to their fundamental question, "What does this bleeding mean for my baby?" One woman shared how she felt having to leave the emergency department still unsure of what the bleeding meant for her:

> You'll have to have an ultrasound… and I was like, "Okay, you can't tell me anything else?" They're like, "No, we really can't, until" [the

> ultrasound]…it was hard to leave and be so uncertain about what was happening with my body.
>
> I thought I might have had a miscarriage when I left and that they weren't sure and that until there was an ultrasound…but I was sort of, why don't they get me that? That was the one thing I remember thinking when I left there… if you're not sure if I've had a miscarriage… can't you do one [ultrasound] and just see?

Another woman recounted;

> The doctor did a quick ultrasound and he said everything looked normal but it wasn't his area, so he wasn't totally sure and he would order an ultrasound for the following day, and I just had to wait for that.

She elaborated about having to wait until the next day for a formal ultrasound and how this impacted her:

> I would have wanted it [the ultrasound] that night …if I could have just gotten a concrete, real, clear ultrasound and them be like, everything looks good….actually knowing at that point in time would have been ideal because you toss and turn all night. You're still worried because no one was actually able to say, "Things are perfect," or "Things are just exactly as they're supposed to be," instead of, "Well, let's just get another opinion, because I can't quite tell because this ultrasound isn't as good as the ones that they have." I'm like, well get the good one!

Even during the ultrasound examination women are left guessing as to what could be happening with their pregnancy. One woman expressed:

> I was just so frustrated, like he [ultrasound technician] wouldn't tell me if there was a heart beat or no, it was totally noncommittal. "Well we could, we couldn't, it's early, we might hear it, we might not".
>
> I wanted to know, either way, like I just wanted to know. Because it had been so long [a time] of just spotting and it would stop for a day and come back and I thought, oh maybe it's nothing, like I just wanted to know so I could prepare…It was a baby to me, so like I wanted to be getting in the frame of mind that I'm not going to have that baby. Just stop thinking of baby names for a little bit.

Uncertainty in waiting.

Some women expressed frustration with the uncertainty in the waiting room, including the length of time they would be expected to wait, as well as what their priority in getting care would be. Women mentioned waiting was arduous in part because it was not clear how the priority system of the waiting room operated.

> Because a lot of people don't know, how does the process work? … Is there one before the other or is it just first come, first served, right? I think that's hard too because you don't know how much time it might take, it could be 20 minutes, it could be five hours. So you don't know what to expect.

Another woman voiced her confusion adding, "…is my case urgent or not …I don't know, of course I'm not dying…but it was unclear to me whose cases were more urgent or not more urgent than others." As well another woman continued;

> You're in a complete unknown, so it's hard, just sitting there, being like, okay are they going to call me in 10 minutes or are they going to call me in 4 hours? Can I go and get a drink or do I have to just keep sitting here and waiting.

Summarizing her experience of waiting one woman offered

> Waiting in an emergency room is awful. I don't know if there's anything worse than that. It's awful waiting. Waiting is definitely the worst part. Just not knowing…you kind of just sit and wait and think and think and think and maybe think the worst until more information comes back to you.

Interestingly some women felt that waiting was in way a comfort:

> On the one hand I was feeling, naturally, some comfort … that they weren't going very quickly because it made me feel like they didn't think it was a concern. So on the one hand it was like, oh my gosh, I've been here seven and a half hours. On the other hand it was like, oh, well the fact that I'm not a priority means that they're not concerned, which also brought some comfort and relief in that.

Similarly another woman said, "Is this not important enough, really? But, I guess a waiting room, maybe you could be glad that obviously I'm okay or they'd have me in there faster, right?"

Pregnancy Adds a Unique Dimension to Waiting

Participants asserted that the state of being pregnant added a unique dimension and perspective to their waiting experience. These women felt very strongly that being pregnant meant the existence of two persons, of two patients.

> This is important, I have a baby, you know, let's just get on things and so when you're waiting, you're like, well why doesn't anyone care about me and my baby? There's not just me, there's two of us that need care right now.

One participant echoed this very eloquently and said:

> There's just something very fragile and vulnerable about an expectant mother, I think, because it's sort of, like, two patients, you know? I just felt like there really wasn't a lot of concern for the unborn child, right? I mean if I look at it now, that's probably what is most…what was lacking, is that empathy for the baby.

This woman affirmed:

> It's a little different when you're dealing with someone who's pregnant...there's a different experience because the person who's pregnant is thinking for two. I wasn't making that decision for me. I'm not a typical user of emergency services...but when I was thinking about my baby, I thought that I would be negligent if I didn't go [to the Emergency Room].

Elaborating further, one woman shared a situation where she waited in the emergency room with an injured family member. She recounted;

> Oh this was so much worse, [waiting while pregnant and bleeding] I've taken….my brother needed stitches and I'm like, oh my god he's losing a lot of blood, but you know that you're not going to die because of it. But in this case, I'm waiting, thinking oh my god, am I going to be…is my baby okay? Am I still going to be pregnant tomorrow?

Likewise, another participant compared waiting in the emergency room while she was sick with the flu, but joked that in this instance it was "kind of a nice break...I can have time on my own! I'm in pain a little a bit, but it's a break". In contrast she noted that when she was waiting while pregnant she was much more anxious, "All I could think was, is my baby okay? You're very much worried about how the baby is".

While not all the participants explicitly described their experience of waiting in terms of it being different, it was clear they perceived that being pregnant was not merely a state, but implied the existence of another human for instance saying, "it was a baby to me", and referring to a spouse as "the father of the child".

Additional Stressors Added to the Burden of Waiting

Participants described the existence of additional stressors added to their burden of waiting such as; family obligations including the care of other children and the disruption of their spouses' schedules, the inability to leave the waiting room, and having to wear a hospital gown.

One participant recounted how staff repeatedly asked her if she had someone who could look after her older child who had accompanied her to the

emergency room, explaining that if she required any procedures or diagnostic tests the child would not be able to accompany her. She stated, "It just added to my stress level, that I didn't know what was happening and then I had to worry about all these arrangements on top of that". Another woman, who also has an older child remarked that she left the child at home with her mom;

> I think if we had had to bring him to the hospital it would have been really difficult because chances are my husband would've just been taking care of him. That definitely made me feel comfortable knowing he was home, safe, sleeping with my mom while I'm here at the hospital

Women described feeling anxiety about the impact that the bleeding and subsequent emergency room wait had on their spouse. Women expressed concern that their spouse had to miss work hours. One woman relayed, "So that was another stressor on top of it because now I was affecting his work schedule".

The inability to leave the waiting room was mentioned as a source of additional strain. "You don't want to leave because you're worried you're going to lose your place in line if you step out. I didn't even want to go to the bathroom, because what if they call my name? Having to stay in the waiting room was an encumbrance as revealed by one woman as she explained that she would have liked to have had the option to leave the waiting room in order to get food for her other child. She wanted to have the option to leave the waiting room in order to help distract him; for instance she noted that he was eager to move around and she would have liked to be able to take him for a walk; having to distract her son with limited means created additional anxiety.

Several participants corroborated that being required to change into a gown was unexpected and was a significant source of added tension to their experience.

> They make you get naked and I was like, what in the heck is going on? So I had to go in a change room, change into a gown, and I was like, holy, this is intense! …I didn't like that part.

Further illustrating this, one participant said, "It was just one more thing just to totally stress you out in an already kind of stressful [situation]…". While another woman asserted, "Why I was in a hospital gown is half of what made me a little uncomfortable".

One woman described that during her hospital visit she felt as if she was a "rebel against the authority" and that this made her feel conflicted. She admitted that staff attempted a couple times to have her visitors, including her spouse, leave but that she insisted her spouse stay. She also recounted that the staff wanted to insert an intravenous line and that when she confronted them and asked them to explain why she needed it, the response was simply "that's just what we do". Moreover, she remarked that the emergency physician tried on more than one occasion to get her to acquiesce to having a pelvic exam. She refused, explaining that she was uncomfortable with the idea and preferred to have an ultrasound prior to the pelvic exam. She summarized;

> They're helping you, and they're an authority at that point too, and you don't want to stand up to that, but you also don't want to miss out on something that would be helpful and it's tough… It puts more pressure on

me to not be seen as difficult by going up and asking these questions or refusing a service.

False Hope

Two women explicitly declared that they resented being presented with false hope about the possible meaning of their bleeding.

> Like I know that you can have spotting in early pregnancy, but I mean this was heavy bleeding and the doctor… he said, "You know, it's not necessarily a miscarriage, it could be implantation bleeding" and at that point, I mean I didn't want to be given any false hope, because I was already so upset. I know he was just telling me all the possibilities, but in the back of my mind I didn't want him to give me false hope.

Likewise, this woman shared, "I was frustrated that they gave me hope and then took…didn't give me hope. I didn't know what I should think, I didn't…I just didn't know what I should think or do ". She further explained:

> So I was totally stressed and then the doctor comes out and says, "Well, you're either not sure of your dates or it's not a viable pregnancy." And that, to hear a doctor say, "Oh, maybe you have your dates wrong," like, you kind of go, maybe I do! Like, I just, I don't know how to describe it. It's like you're down, you come up a little bit with some hope, and then you know the hope is almost false, and it's going to bottom out on you.

Knowing

Some of the women recounted that they knew or intuited what their bleeding meant prior to receiving confirmation on the viability of their pregnancy.

For instance, one woman affirms, “I pretty much knew based on the amount of blood and the way I was bleeding that it was a miscarriage” while another recalled, “I think in my heart of hearts I knew it was a really bad situation”. Yet another woman said, “I was like feeling funny because… I didn’t have any pregnancy symptoms that were overwhelming”. Finally another related, “…mother’s intuition, I kind of felt like I knew the baby was still there at least”.

Previous Experience

Previous experience with respect to prior pregnancies played a role in how women felt about the bleeding in their current pregnancies. One woman reflected, “I think I just associated bleeding with miscarriages, and because I hadn’t had bleeding with my other pregnancies, it was so new to me and it was frightening”. Similarly, another woman echoed, “...the spotting worried me a little bit when I first saw it, just because…like with my first pregnancy, never spotted, nothing….happened bad at all, so I thought, oh boy”. Likewise, a woman shared, “I was trying to be positive but at the same time kind of had a suspicion that something was not okay, because I didn’t have any bleeding in my other two pregnancies”. Another woman talked about how with her first pregnancy she was more cautious and she held in the back of her mind that something could happen, but the experience of having a healthy child resulted in her being “just completely excited and happy” with this pregnancy. She said she put all the fear out of her mind and so bleeding during this pregnancy caused significant distress and shock as she wasn’t anticipating any complications. Drawing on her previous experience another woman reported that during her pregnancy she was, “a little

bit apprehensive just because of what I experienced before" and that when she discovered she was bleeding she "panicked".

Staff Attitudes

The women's perception of the attitudes among the staff they encountered varied and existed on a spectrum from "calm" and "supportive" to "cold" and "gruff". The impression of the triage nurses was mostly positive- "the girls where you check in were really good…they were really approachable". Likewise another participant warmly recounted, "At triage, right away those nurses were unbelievable, just calm and gentle and their voices were really soft and knowing that what I was going through was obviously hard for me". However, yet another woman reported feeling as if the triage nurses could have been "more sensitive" to her needs with respect to her older child. She related that when she was told that she couldn't bring her older child along if she should need an ultrasound she offered to put him in a stroller and explained that he wouldn't be disruptive. She further elaborated that she felt as if they conveyed a disapproving attitude, narrating, "We'll try to see if it's okay but, you know, they don't like it".

The overall perception of the nurses was favorable and the participants described them as "great" and "supportive". Similarly, another woman affirms that despite the conflict she experienced with the, "first nurse, when I first was resisting the IV", that in general the "nurses were unbelievable", "consistently kind", "respectful", "calm" and clearly tried to "advocate" for them with the doctor about patients and their lengthy wait times. Another woman observes that

the nurses who cared for her were “really good” but regrettably, “there’s no one to just sit and chat with you…no one to just hang out for 40 minutes”.

Participants’ impressions of the doctors they encountered was typically less positive. One woman related how the emergency doctor who assessed her was, “very gruff and kind of short and to the point” and did not offer an explanation beyond- “Well that’s just what we do” when she asked why she needed a vaginal exam. Moreover, she expressed that when she opted out of the vaginal exam that the doctor “didn’t seem happy with my decision” and “that not being treated that way, like my refusal of a service was a problem, would have been really nice”. Another participant also mentioned that the emergency doctor who assessed her “didn’t seem really supportive, like he had another place to go”.

Conversely, another woman described a positive experience with the emergency doctor who examined her after having her ultrasound. She noted that he took the time to gauge where she was at emotionally, explained what she could expect both physically and emotionally during her miscarriage and shared a personal story of his own loss with her, which she indicated “actually really helped”. Moreover he provided a referral to the Early Pregnancy Loss Program to monitor her for follow up. She summarized her experience in the emergency department as follows,

> I felt like I was really being looked at and treated and they were thorough in making sure that it was a miscarriage and that everything else was okay and that I was treated properly.

Although she did identify a particular health care provider, one participant's overall perception was that "in the emergency, that they weren't very compassionate to the fact that I was potentially having a miscarriage". While another woman described her encounter in this way:

> That doctor [the radiologist], like I just remember how cold she was about it. I'm sure, maybe you see 15 miscarriages a day, but it's like, we're all going through it. Like it's our first miscarriage, or not, either way it's a bad time. She was just so cold.

Social Support

All of the women described their need for some type of emotional support while waiting to discover the meaning of their bleeding, and in most cases this was the comfort of a spouse. All of the five women who presented to the emergency department for assessment of their bleeding were accompanied by their spouse for all or part of their encounter. The women asserted that the support of their spouse is what kept them calm and grounded.

> I just remember I was glad my husband was there…just that compassion and someone, you know, really understanding…even just being able to put my head on his shoulder and hold his hand, like just not feeling alone and totally emotionally…it keeps you together a little bit, right?

One woman described the impact of having her husband with her, "he was really, really supportive. I tend to be sort of the emotional…He tends to be more sort of even and calm, so he was definitely the one that kept me calm". Another simply said, "I was so glad he [spouse] was there".

One participant, who was initially unable to contact her spouse when she went to the emergency room, relays that she texted with friends and family while waiting in the waiting room. Furthermore, one of her friends volunteered to stay with her until her spouse could make it to the hospital.

> Honestly if I didn't have, at the beginning before my partner had come, if I didn't have my cell phone to text and I didn't have my friend there with me, it would have been a much more terrifying experience… honestly, because they were able to help keep me calm when I was feeling really worried.

Barriers to support.

Some women recalled being separated from their spouses and that they found this very distressing.

> There was one point when I was in the treatment area waiting room and they told him [spouse] that he'd have to leave. Even though there was nobody else in the waiting room and, I mean, it was quite emotional. I needed him there.

Another woman revealed

> There was a couple times that they came back to try to clear visitors out and well they weren't leaving because I wasn't wanting them to leave. It's a tough place to be in when you're sitting back there, you need people with you, so anyway, I thought that was an interesting experience in terms of the setup not allowing that and us having to feel like we were breaking the rules in order to have that, was hard for me at that point.

One participant narrated how her husband was not allowed to accompany her into the ultrasound room. She talked both in terms of her need for support but also her concern for her husband's emotional well being. She felt it was important for both herself and spouse that as "the father of the child" he should have been should have been part of the experience. This includes being present in the ultrasound and being provided the opportunity to ask questions. The inability to have her spouse with her during the ultrasound is especially poignant as it was during this diagnostic exam that she was told by the radiologist that the test indicated that the baby had no heart beat and that it was indicative of a miscarriage. She then described being returned to the waiting room and being reunited with her spouse, "I walked into the waiting room where he was waiting, I took his hand...It was pretty sad". She revealed that her spouse was "very hard hit….having the opportunity for him to be there throughout the whole process would have been better".

Another woman shared;

> My husband couldn't be with me in the first room…it would have been nice to be able to have him there…as support, even to be like, "Okay, you know, everything's going to be alright," and what not, because everyone else is so busy there.

Moreover, she offered advice to other women who go to the emergency room to be assessed for bleeding:

> Have somebody with you. You don't go alone or, you know, when you do go in to be seen, that you say, "No, like I need my significant other or my friend or whoever it is, with me."

Lack of Privacy

All the participants mentioned that they felt a lack of privacy to some degree during the assessment of their bleeding during pregnancy. For a few of the women this lack of privacy began the moment they walked in to the emergency room and presented to the triage desk. When presenting to the triage desk, "I almost whispered like, I'm having a miscarriage, or something that, you know, you don't necessarily want people to know and you're quite upset" voiced one woman. She also noted that at the time of her visit, "it was quite chaotic and busy, which makes it a little bit harder because everyone can kind of hear what you're saying". This lack of privacy continued while women waited in the waiting room. This was particularly distressing for some participants who described feeling uncomfortable that the waiting room afforded no privacy especially in light of their intimate and emotional concern.

> I had tears on and off in the emergency [waiting] room, so that was hard and then it's kind of awkward because they take blood in there too, so then everybody's like, "Oh, she's getting blood, let me look'". It was kind of like emotional just because you're already stressed out and then everybody's looking at you wondering and asking…

She further relayed that some of the other patients in the waiting room asked her why she was waiting, what was wrong with her and why she was upset. She

revealed that, “It was hard, just because you’re not in the mood for that kind of stuff”. Similarly, another woman shared, “I was like crying and just everyone can see… that part was a little bit uncomfortable”. One participant remembered being conscious that people were wondering why she was waiting in the waiting room, especially as she appeared obviously pregnant- “Some people looked at me and I thought they’re thinking I’m losing a baby that’s quite far along”. One woman recounted that while in the waiting room she was talking on the phone “about something that was pretty private to me and I didn’t really have a place to talk about that”.

Some women expressed that the waiting room was particularly unpleasant and that they would have preferred an alternative to the waiting room environment.

> It would have been nice to be somewhere separate, at least for the first little bit to calm down, because you kind of become a spectacle when you’re crying and people become more curious about, “Oh, this girl’s crying, she’s not bleeding or evidently in pain, you know, what could be going on?” that kind of thing. Maybe nobody else cares, but you feel like everybody’s looking at you.

One participant mentioned she would have preferred to wait with other women who were going through something similar rather than wait in the general emergency waiting room. Another woman shared that her experience of waiting was difficult owing in part to hearing another woman talking euphorically on the phone and telling her husband how happy and excited she was that she was

having twins. She reflected, "I really just want to have one that's alive in here, I just thought, ugh, I didn't want to…I don't know, I just…didn't want to see anyone else. I didn't want to be around anyone else. She further opined,

> If there could be an early pregnancy centre you could go to, like in a perfect world… and they're kind of sensitive to what's going on, they don't have to worry about the diabetic and the broken bones…

For some women, their violation of privacy continued once they were in the assessment rooms. One participant discussed how she was placed in a room with only curtained walls, "you can hear everyone talking in the rooms next to you too, and I definitely was aware of that". The situation was particularly difficult for her especially when she was having intimate conversations about vaginal bleeding. Moreover, she recounted, "every time they [staff] left I had to reclose the curtain because it kept opening. I was aware of the fact too that I was in a hospital gown, which made me a little bit awkward and uncomfortable…" Another woman told of being in a bed in the hallway when her beside ultrasound was performed, although she did not elaborate on how this made her feel.

Contrary to the experiences of some of the other women one participant remarked that while she was being examined she was put in a room that was "quite private", saying, "…it had a door to the room, it wasn't just a treatment area where it just had a curtain. So that sort of privacy was very nice…just because it was such an emotional thing".

For one woman, the violation of her privacy was most difficult when she found out that her bleeding indicated miscarriage. She noted that when she left for

her ultrasound she was told she would be returning to the private room she was in previously but after she was instead returned to a waiting room. She reported feeling confused and disappointed that staff had not followed through on returning her to the privacy of the first room so that she could share the news of the pregnancy loss with her husband.

Provision of Information

All of the participants mentioned that the amount of information they received during their visit was inadequate. The information that was lacking varied among participants and included, what was happening during the assessment of their bleeding, the cause of their bleeding and what to expect after leaving the emergency department.

For instance, one woman recalled that during her visit to the emergency room no one explained to her what was happening during the assessment process. She said that she had blood work and a urine test done but, "Nobody said, 'We're going to take your blood, did you know what it was for?' No. I still don't [know what it was for] ". Moreover, she reports that when she asked questions about the process such as the necessity of a pelvic exam and an intravenous line, staff responded with- "Well that's what we do". Similarly another woman pointed out, "It's nice when they tell you what's going on….being examined and then them just saying- 'Oh, somebody will talk to you about it', and then leaving…I don't like that…I like to be given all the information".

Many of the women reported leaving the emergency department without an explanation as to what may have caused their bleeding. Illustrating this, one

woman recounted, “No one even said anything about bleeding in pregnancy to me….No one said anything to me that gave any kind of explanation or understanding of what was going on”. Another woman asserted that she would have preferred if the doctor had more information to give her, even suggesting that it be in the form of writing, saying that she might trust it more and it would make her feel better about it.

The women also related not being prepared for what to expect in the case of a non-viable pregnancy.

> I think they could have been a little bit more forthcoming about, or at least asked me, “Do you need some, do you want me to go over maybe some of the things that might happen?” … I knew this is a miscarriage, and I know what’s going to happen, but I didn’t know exactly what was going to happen because this was much further along than the last time…I was spotting and I had this anxiety too, after I left. I wondered what it was going to be like when I actually start the miscarriage.

Another woman expressed similar dissatisfaction saying:

> [They] didn’t tell me what to expect if it wasn’t a viable pregnancy, I didn’t have any information going forward, and I found out quickly, like, a few days later, that it was not a viable pregnancy. So that left a bad…I was just, I was frustrated.

Information Seeking

Women sought information from a variety of sources to help them evaluate bleeding in their pregnancy; including, what they were expected to do

about it, what it could mean and what to expect. Many participants reported that they had sought information from sources other than the doctors they encountered in their emergency visit. These sources were most often friends or family members, the internet or other health care providers.

Friends and family members.

Talking to friends and family members was mentioned as a means of information seeking. When one woman's bleeding began she described calling her friends that had also had bleeding during pregnancy. This provided both information and comfort as her friend told her, "I spotted, no problem. I have my kids, it's fine, it's fine". She also recalled relying on her friends for information on what to expect in the case of a miscarriage.

> I had to phone a friend who had a miscarriage and say, "I think I'm having a miscarriage." So she told me what to expect and who to call… My friends were the best source of information good and information bad, once I knew [I was having a miscarriage].

One participant relayed how she spoke with a family member to ask advice and seek information on how to proceed since she was bleeding. She said, "I called her [family member], kind of like, I don't know what to do, just some reassurance. I'm really grateful I had her ". She elaborates that her family member explained what the bleeding could mean, where to go for assessment and what to expect during the assessment.

The internet.

Several participants talked of using the internet to search information on spotting or bleeding during pregnancy. Mostly women indicated that the internet, while it did serve the function of providing information, did nothing to relieve their anxiety. A couple of the women noted that the information they received on the internet was contradictory and inconsistent. For example, one woman stated, "I Google, and of course you could find any answer you want to anything. I had spotting and it was fine, I had spotting and it wasn't fine". Another woman talked of using the internet as a resource for what to expect during her miscarriage and plans for subsequent follow up. She indicated that her online research suggested that there was no need for further follow up so she opted not to follow up with her family doctor.

Opinions were mixed among participants whether or not internet research was helpful or harmful.

> I don't think it was helpful because it scares you, right? There was reassurance though because there were a lot of reports…that said, "I had a healthy baby, I was worried and I had a healthy baby, and everything's fine…"

Another woman who also researched the causes of bleeding in pregnancy said, "I decided to look things up on the internet, which was a mistake because it's all bad stories". Furthermore, she advised other women with bleeding during pregnancy "Don't read the internet! Don't read anything on the internet, which I know everybody does it and then I think that's where most, the biggest concerns come

from". Similarly, another woman affirmed, "Don't Google it, just don't Google it!".

Other health care providers.

One participant recalls hearing that she should not go to the emergency room when bleeding during pregnancy so she called Health Link Alberta for advice and was directed to the emergency room. Health Link is a 24 hour a day telephone line that provides advice and information on health related concerns. Another woman who was also unsure what to when she noticed bleeding called the clinic of her obstetrician and was directed to emergency by the clinic secretary. Two women reported contacting the Early Pregnancy Loss Program to access information on what to expect during a miscarriage, one was referred by the emergency physician and the other self-referred as advised by her friend.

Other participants related that after their emergency visit they followed up with their family physicians to discuss their pregnancy and the possible meaning of their bleeding. One woman said this about talking with her family physician: " [it] was kind of nice because she was a mom as well, so when I went to see her, it was really reassuring and she's a super researcher, so she sat there with me". Another woman reported that she was "really grateful" for the information that was provided by her family physician with respect to what to expect in the future with her pregnancy. Saying if her family physician, "hadn't told me that it [bleeding] could happen more, I probably would have panicked again".

Hindsight

Participant opinions were mixed on whether or not their perception of their visit to the emergency department was valuable or futile. One woman revealed, "If I had hindsight, if I had the 20/20 vision of recognizing what was going on, I wouldn't have gone to the ER. She further explained:

> No one told me that at the hospital, but when my GP told me that they don't do any intervention until 20 weeks anyway, I wouldn't go back to an ER until after 20 weeks. That's what I would tell other women, unless you're bleeding fresh, red blood a lot, like you're filling a pad, I would not waste my time in the emergency room

Some participants commented that they went to the emergency room in search of immediate answers.

> I think you need to go where you can go and have somebody immediately tell you something, like even if it's just somebody to examine you and while they didn't give me any answers, there's something reassuring about being at a hospital and with doctors.

Likewise, another woman said, "it turned out, like it was actually a good thing I went, I think, for all the testing that I got done and just for the peace of mind, too". Equivocally another woman said, "I probably could have waited, but because I was so upset and you're in the moment and then you're thinking worst case scenario, you want it to all be resolved as fast as possible". Conversely this woman maintained, "If it was the exact same thing happening again and I'd

already been through it, I wouldn't even bother going to a doctor. I know that sounds terrible. But there was nothing anyone could do".

Summary

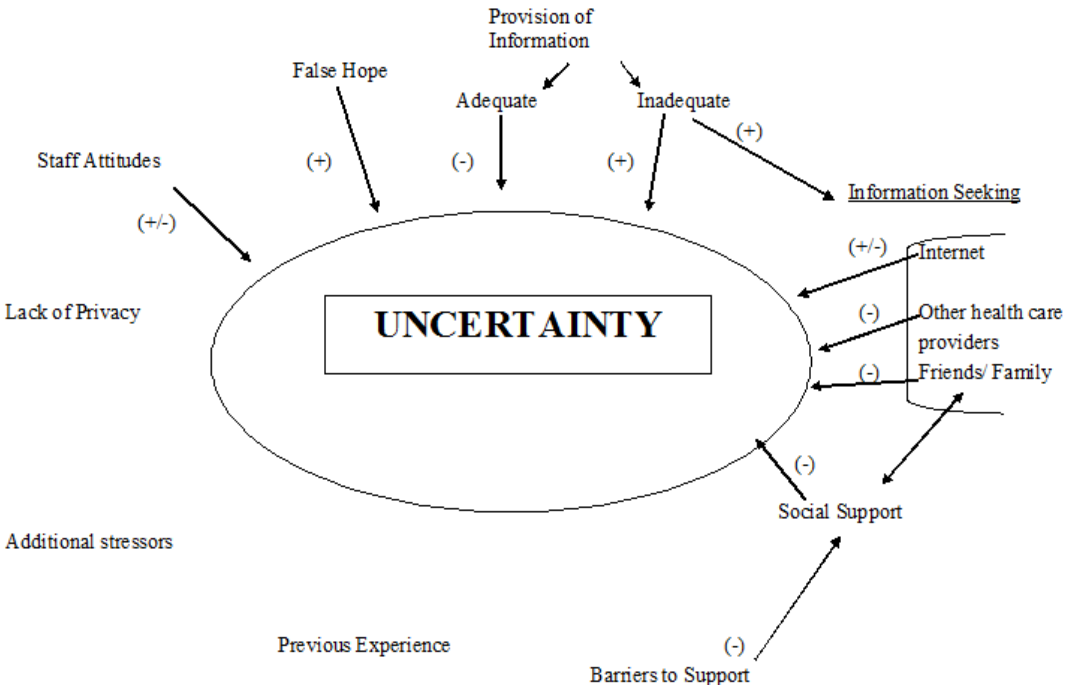
Waiting among women with bleeding during pregnancy.

The core of the experience of waiting while pregnant with bleeding was uncertainty and how this was mediated by external factors. For instance, information provision both increased and decreased uncertainty based on its adequacy; that is, adequate information led to reassurance and decreased uncertainty while inadequate information provision resulted in increased uncertainty and led to information seeking. Largely, information seeking led to decreased uncertainty especially when it was sought from social supports. However, the benefit of the internet as a source of information was mixed, with some women finding reassurance and others finding it worsened their anxiety. Social support unmistakably reduced uncertainty, both directly and also indirectly through the provision of information. Reports of staff attitude were mixed with respect to their effect on uncertainty and were contingent on the woman's perception of the staff's bedside manner. More specifically, women who regarded the attitude of the staff positively expressed less uncertainty than did those who felt that their health professionals' were uncaring or not forthcoming. Uncertainty was not reduced by the experiences a woman had in a previous pregnancy, regardless of whether those outcomes were positive or negative. False hope provided by health care professional resulted in increased uncertainty for women experiencing bleeding during early pregnancy. Finally, additional stressors such

as interfering with spousal work schedules, not being able to leave the waiting room, as well as, lack of privacy placed additional strain on women waiting with bleeding during pregnancy.

In summary, inadequate provision of information and false hope led to increased uncertainty, while adequate provision of information and social support reduced uncertainty. Information seeking and staff attitude had a mixed effect on uncertainty among women and was related to the adequacy of the information and the interaction of the staff. Lack of privacy, barriers to support and additional stressors placed an additional burden on women while waiting but did not necessarily increase uncertainty.

Figure 1. Concept Map: Interplay between uncertainty and mediating factors



Chapter Five

Discussion

In this chapter an overview of concepts that emerged from women experiencing bleeding in pregnancy will be provided and how these concepts relate to existing knowledge will be explored.

Uncertainty and Waiting

Mishel (1981) explored the role of uncertainty in patient experiences of illness and developed a mid- range theory and model of *Uncertainty in Illness.* Although pregnancy is not an illness this model has been adapted and applied to assess uncertainty in low-risk and high-risk pregnancy (Ashcroft, 1995; Clauson, 1996; Handley, 2002; Sorenson, 1990). Uncertainty is defined as the inability to determine the meaning of events and/ or to predict outcomes accurately (Mishel, 1981; Mishel & Braden, 1988). Moreover, when an event is perceived as uncertain it is evaluated as a threat because there is no clear conceptualization of what is going to happen (Mishel, 1981).

Uncertainty emerged as a prevailing concept throughout the experience of waiting while bleeding during pregnancy. This would seem to confirm that uncertainty can be a predominant feature in pregnancy (Gupton et al., 1997; Handley, 2002; Sorenson, 1990). These uncertainties may stem from the physical and emotional changes intrinsic to pregnancy, as well as symptoms that may mimic disease such as nausea, pain and fatigue (Handley, 2002). Although the potential for uncertainty is inherent in all pregnancies, it may be intensified in situations where bleeding occurs. It also seems likely that another factor is

mediating this uncertainty and this is the amount of distress that women associate with the uncertainty they are experiencing. For instance, if uncertainty shifts from thoughts of- “What will my baby look like?”, to thoughts of-“Will I still be pregnant tomorrow?”, with the latter being more likely to produce anxiety. Moreover, literature supports that higher levels of uncertainty are associated with higher levels of stress and poorer psychological wellbeing (Clauson, 1996; Giurgescu et al., 2006; Mishel, 1984).

The perception of waiting among participants was inexorably linked to the concept of uncertainty. Many of the concerns that arose from women with respect to waiting and uncertainty correspond to those proposed by Maister (1985):

- Anxiety makes waits seem longer
- Uncertain waits are longer then known, finite waits
- People want to get started
- Unexplained waits are longer then explained waits
- Unfair waits are longer then equitable waits
- Solo waits feel longer then group waits
- Occupied time feels shorter then unoccupied time
- The more valuable the service the longer the customer will wait (Maister, 1985, p.1-9)

Most crucial is the proposition that anxiety makes waiting seem longer. Most women with bleeding during pregnancy are likely to experience an enormous degree of anxiety around the fate of their unborn child and possibly their own health. Maister (1985) submits, “The most profound source of anxiety in waiting

is how long the wait will be" (p. 5). If a woman is told the doctor will see her in twenty minutes, the woman will relax into acceptance of this wait, instead if she is only told the doctor will see her "soon" then she spends the whole time nervously anticipating when the doctor will call her in (Maister, 1985). Women mentioned feelings of uncertainty and anxiety surrounding how long they would be expected to wait before being assessed by a physician. This mirrors what occurs in the majority of emergency room settings, patients are never told how long they can expect to wait. Accordingly, participants voiced confusion and uncertainty as to how the priority system of the waiting room operated; and as Maister asserted, women remained in a state of apprehension about whether their priority in the line was being preserved which further increased anxiety and the perceived waiting time.

The presumption that people want to get started is interpreted by Maister to mean that anxiety is much greater while waiting to be served then it is while being served. This is true even if the latter is longer and Maister suggests that this is related to the fear of being forgotten. For women with bleeding in pregnancy waiting to be seen by a doctor likely felt much longer than the waiting once she was inside the emergency room even if the chronological time was longer. This may relate to the perception that while one is waiting in the emergency waiting room nothing is being done, yet once one is inside the emergency department they are more likely to feel as if someone is taking care of them. One participant illustrated this by recounting how she felt while waiting to get a room in the emergency department:

> Well at the time, like you think, oh my god, time's wasting people. Why aren't you seeing me? Like this is important, I have a baby, you know, let's just get on things and so when you're waiting, you're like, well why doesn't anyone care about me and my baby?

Women described uncertainty about what to expect during her visit to the emergency department, which relates to the premise that if a wait is unexplained it will feel longer than one that is explained. "Waiting in ignorance creates a feeling of powerlessness" and lack of information adds to the uncertainty about the length of the wait (Maister, 1985, p.6). Therefore, if during the emergency visit a woman is provided limited or no information about what to expect, her uncertainty will increase and her perception of time spent waiting is likely to be increased. For example, it may seem that there is no logic to waiting in an emergency department, where priority for care is determined by the severity of a person's illness rather than the order in which he or she arrived in the emergency department waiting room. To those who do not understand the triage system, the order in which people are called is enigmatic. This was echoed by sentiments from participants; they expressed confusion and uncertainty with respect to the priority in which they would receive care. Women remained in a state of apprehension about whether their priority in the line was being preserved and this again adds to increasing the anxiety of the wait, which will seem longer then a relaxed wait (Maister, 1985).

The next two assumptions are related- there is some comfort in waiting with someone rather than waiting alone, and boredom will skew the perception of

the time waited. For women in this study the ability to have a support person accompany her while waiting provided support, comfort, and helped assuage anxiety as well as function to alleviate boredom.

Finally is the notion that the more valuable the service the longer a person will wait. Women with bleeding during pregnancy have limited options of where they may seek answers about the cause of their bleeding and its possible meaning, therefore they will likely wait as long as is required. Moreover, what could be more valuable than determining the outcome of bleeding that can threaten your unborn child? Waiting is the agony of knowing with certainty what one wants to happen but being uncertain and terrified about what will happen (Bournes & Mitchell, 2002).

Pregnancy Adds a Unique Dimension to Waiting

It was apparent that for women experiencing bleeding in pregnancy being pregnant was not merely a state; women ardently felt that two human beings were in existence and in need of medical attention. This is not meant to spurn a religious discussion about the point in which life begins, but has more to do with each woman's individual concept of the pregnancy and if that constitutes the existence of a child.

In a review of evidence on grief following miscarriage, Brier (2008) discovered partial support for the view that there is an association between perceiving the pregnancy as real and grief following miscarriage. Mixed results were found on the relationship between grief and other variables such as degree to which the pregnancy was desired, the importance of the pregnancy and gestational

age at loss (Brier, 2008). Moreover, actions such as naming the baby, purchasing items for the baby or making changes in anticipating the baby's arrival were linked with higher levels of grief following miscarriage (Brier, 2008). Although this particular review focused exclusively on grief following pregnancy loss, there exists a paucity of evidence on bleeding during pregnancy not associated with pregnancy loss. Notwithstanding, it may be possible to anticipate some similarities in women experiencing bleeding in pregnancy. For example, the degree to which a pregnant woman views the baby as "real" would certainly influence the emotion she felt about the existence of two persons, two patients. Likewise, it seems reasonable that the more women perceive their "baby" to be real, the more anxiety they would feel with the onset of bleeding, perhaps feeling that the child's life was in jeopardy; thus waiting while pregnant would seem that much more devastating.

Additional Stressors Added to the Burden of Waiting

The care of other minor children and hindering a spouses schedule was cited as a source of additional strain for women waiting with bleeding during pregnancy. These family obligations added both to the burden of waiting as well as increased the uncertainty of the situation. For instance, the burden of having to distract another child while in the waiting room, or make alternate arrangements for the care of a minor child. Correspondingly, in a study of women experiencing complications in pregnancy, multiparous women experiencing complications in pregnancy had increased uncertainty scores compared to nulliparous women (Ashcroft, 1995). Ashcroft (1995) suggests that this is as a result of a woman

being separated from family including other children while she is admitted to hospital for pregnancy complications. Women also mentioned that they were concerned how the bleeding and resulting emergency room visit impacted their spouses' work schedule. Having to now consider the impact on their spouse would unquestionably increase distress and uncertainty.

Furthermore, women recounted that being confined to the waiting room added to their distress. It caused them to focus more on waiting, eliminating the possibility for other distractions. Moreover, it confined them to an area in which there were many others waiting during an intimate and time of intense emotions. One woman specified that she would have liked to have the option to leave the waiting room so she, "could go for a walk and kind of get away from all the rest of the people there surrounding you. You could kind of walk away, take a breath, try to calm down, those kind of things". Likewise, Catania et al. (2011) found that patients believed that having the freedom to leave the waiting room would greatly improve their waiting experience.

Women felt the need to conform to the established rules and the policies, yet they were conflicted when they recognized that these policies served to increased their distress and uncertainty. This distress that women endured when being separated from their spouse or other source of support is echoed by the concept of "ambiguous turbulent lull" which emerged from family members waiting for loved ones in a critical care waiting room (Bournes & Mitchell, 2002). This encompasses the "torment that people experience when choosing to when choosing to conform with a system that has kept them separated from their loved

ones" (Bournes & Mitchell, 2002, p.65). Despite being discontented with separating from their spouse, most women did not insist that their support person be allowed to stay. It could be that women wanted to be seen as the "good patient" or conforming to the rules as they expected this would be the way to get the best quality of care for them and their baby. Possibly they were uncertain with how staff would react to their assertion that their spouse stay. Similarly, women expressed being uncomfortable with having to wear a hospital gown but complied; perhaps again they conformed despite their unease as they wanted to portray themselves as an agreeable person deserving of high quality care.

False Hope

Women with bleeding during pregnancy resented being offered false hope about the meaning of their bleeding; false hope functioned to create doubt and thus increase uncertainty. For instance, one woman indicated that she was very certain of her conception date and was told by the physician that either her dates were wrong or the pregnancy wasn't viable. She offered this as a reply:

> And I went, "Well I am sure of my dates, I have an app on my phone, I've been tracking, I know exactly when this [pregnancy] happened and I'm not unsure of my dates." And she [physician] said, "Well, a lot of women think they're sure and they're not, and you'll have to come back in a week for another ultrasound."

This woman then relayed how this interaction left her feeling more uncertain and distressed, ruminating whether perhaps her app was incorrect or if she had somehow miscalculated her conception date. Interestingly, she did not feel

reassured by the suggestion that perhaps her dates were incorrect and her pregnancy would still be viable.

This reaction to this concept counters Mishel (1988), who postulates that the maintenance of hope depends on the existence of uncertainty and "when the alternative is a negative certainty, uncertainty may be a preferable state" (p. 230). This hypothesis suggests that if the known alternative was pregnancy loss then women should prefer to remain in a state of uncertainty, or "not knowing" where there exists the possibility that the pregnancy remains viable. However, oscillating between mutually exclusive outcomes, trying to prepare for either possible outcome is mentally exhausting. A pregnant woman experiencing bleeding can hardly prepare herself for mourning the loss of her anticipated child while simultaneously engaging in fantasies about her future child. Strategies for anticipating an event's occurrence are often incongruent with strategies for anticipating the events non-occurrence (Lazarus & Folkman, 1984). This is illustrated eloquently by one woman who said:

> I wanted to know, either way…I just wanted to know so I could prepare…It was a baby to me, so like I wanted to be getting in the frame of mind that I'm not going to have that baby. Just stop thinking of baby names for a little bit.

In terms of the experience these women with bleeding in pregnancy, the uncertainty was worse than the idea of pregnancy loss, women resented being offered false hope.

Knowing

Some women described "knowing" the fate of their pregnancy prior to hearing confirmation on whether or not their pregnancy was still viable. Given the retrospective nature of the majority of the interviews it is not possible to separate this intuition from hindsight. Existing literature on intuition with respect to pregnancy loss is scarce. An online abstract that proposes to investigate a woman's experience of early pregnancy loss appears promising in terms of exploring offering how women use personal intuition as a component of "being sure" (Limbo, 2014). Regrettably, there is only an abstract available at present; therefore it is not possible to determine the relevance of the study to the experiences of women with bleeding in pregnancy in terms of "knowing" the meaning of bleeding.

Perhaps this sense of "knowing" was a way in which women coped with uncertainty; this retrospective view on the outcome of the pregnancy created a prediction or expectation of what was to occur, an attempt to create certainty in a distressing and uncertain time.

Previous Experience

Related to the concept of previous experience is the notion of "stimuli frame", an antecedent of uncertainty, as identified by Mishel (1988) and it comprises three variables: symptom pattern, event familiarity and event congruence. Symptom pattern refers to the consistency in which symptoms present so that they may form a pattern; while event familiarity is defined as the "degree to which a situation is habitual, repetitive or contains recognized cues

(Mishel, 1988, p.225). Finally, event congruence is described as the accordance between what is expected and what is experienced. According to the *Uncertainty in Illness* theory, these three variables are inversely related to the construct of uncertainty (Mishel, 1988). Essentially, uncertainty is reduced when the meaning of events can be determined, that is when then they are recognized as familiar and proceed as expected.

But did women with bleeding in pregnancy who had experienced a previous episode of bleeding experience more or less uncertainty? Presumably a woman with bleeding in a previous pregnancy would know what to expect from her encounter in the emergency room; this would constitute event familiarity and uncertainty should correspondingly decrease. Likewise, if a woman had not been previously pregnant or had not experienced bleeding in her previous experience it could be postulated that she would be more uncertain when this bleeding occurred as she would lack symptom pattern, event familiarity and event congruence. Accordingly, women who had experienced previous "normal" or uncomplicated pregnancies were not anticipating bleeding during the pregnancy and thus were unfamiliar with the event and its meaning and therefore experienced increased anxiety and uncertainty. However, the reverse of this does not appear to true; although women that had previously experienced bleeding were able to establish bleeding during pregnancy as familiar, it did not lessen their uncertainty or their anxiety. Possibly women, although familiar with the occurrence of bleeding during pregnancy constituting a familiar symptom pattern, were still unable to discern the meaning of it in this pregnancy. Moreover, women would also have

increased uncertainty as a result of lack of event congruence; whether or not women experiencing bleeding in a prior pregnancy did not prepare them to expect bleeding in a subsequent pregnancy. In addition, women who experienced a poor outcome from bleeding in a previous pregnancy would likely experience more anxiety and uncertainty in a subsequent pregnancy.

Ashcroft found that as gravidity increased so did mean uncertainty scores in a sample of women experiencing complications in pregnancy. Ashcroft hypothesized that women with complications in pregnancy who have been previously pregnant experience greater uncertainty as they may have had complications or negative outcomes in those prior pregnancies and fear a repeat of those negative experiences.

Staff Attitudes

The rapport established between women and their health care providers was paramount in how the women identified their experience of bleeding and how it impacted their distress and uncertainty of the situation. Patient satisfaction has been associated with staff characteristics such as, courtesy, friendliness, professional attitude and responsiveness to concerns (Thompson, Yarnold, Williams & Adams, 1996). Not surprisingly, patients who characterize their interactions with staff as positive are more likely to describe their emergency department visit favorably (Thompson et al., 1996).

The trust and confidence that the women had in their health care providers was a factor in how they viewed and understood the evaluation of their bleeding and its possible implications. Mishel (1988) identifies this trust and confidence as

"credible authority". Mishel (1988) asserts that patients expect their health care providers to take responsibility for providing judgment and recommendations of value. Moreover, when the authority is appraised as highly credible, uncertainty will be reduced via the provision of information on the causes and consequences of symptoms (Mishel, 1988).

The lack of significant interactions with staff, such as being able to engage them in conversation was reported as a source of distress for women awaiting diagnosis after abnormal mammogram (Thorne et al., 1999). Likewise, women in this study noted that the lack of interaction with staff resulted in distress; moreover this was particularly noteworthy with respect to ultrasound technicians. This is possibly due to the ultrasound feeling like the peak of uncertainty and thus a time of extreme stress as it is more likely to provide a definitive answer as to the viability of the pregnancy then the clinical assessment (Dogra, Paspulati, & Bhatt, 2005). Typically, ultrasound technicians simply perform the diagnostic exam and do not provide results or answer questions, but the degree to which these guidelines were followed varied; accordingly the amount of uncertainty, distress and reassurance that the ultrasound provided also varied. One woman discussed how she tried to connect with and engage the ultrasound technician in the effort of humanizing herself.

> I'm trying to make jokes, like "Hey, I'm a relatable patient, help me out." Like nothing, I was just so frustrated; he wouldn't tell me if there was a heart beat or no…

Another woman recounted:

> She [ultrasound technician] was not really interacting very much with me at all and then at the end, you know, I was afraid to ask her any questions and then I finally I said, "Is there anything you can tell me?" And then she said, "Oh, the doctor's going to come in and talk to you about it."

In contrast, one woman reported that the ultrasound reduced her anxiety and uncertainty and she finally felt some comfort. She said:

> I think that was when I finally felt more reassured because she [ultrasound technician] was like, "Okay, everything looks really good," and they did all the measurements again and it was nice because …I got to see the baby and I was like, okay and he's all safe and cozy in there. So at that point…I felt very relieved in that everything was okay.

Sorenson (1990) revealed that ignorance, intolerance and indifference were reactions that consistently emerged from women's description of negative reactions that their health care providers had to their uncertainty. Ignorance was described as the health care provider being unaware of the extent to which uncertainty existed and a lack of awareness of how distressing the uncertainty was for women. Furthermore, intolerance refers to health care providers not being willing to tolerate discussions about women's uncertainties, coupled with paternalistic overtones. Finally indifference is lack of concern, interest or feeling about the woman's uncertainty, or normalizing it without allowing the woman to express it.

Interestingly, it appeared that nurses were more likely to be perceived as supportive and ascribed qualities such as "calm" and "gentle", while physicians

were more likely to be characterized as “gruff”, “short”, and “cold”. The foundation for this was not clear from the interviews and bears more investigation. Possibly it is related to the reduced amount of time that physicians, when compared to nurses, are able to spend with each patient. This is inherent in the structure of the emergency room; the ratio of physicians to patients is less than the ratio of nurses to patients. Or perhaps it is related to the physician being perceived as holding the power; that is women believing that the physician knows what the bleeding means and not being forthcoming with the information. For instance one woman recounted, “It’s nice when they tell you what’s going on….being examined and then them just saying, “Oh, somebody will talk to you about it,” and then leaving”.

Conceivably this dichotomy in the perception of physicians and nurses may also be related to the physician bearing the burden of conveying bad news about the outcome of the pregnancy. However, in at least one situation a physician attitude was described negatively despite the fact that he had not provided any information on the outcome of the pregnancy. Likewise one participant characterized her experience with the physician very positively despite being told she was experiencing a miscarriage. Lastly, it is possibly related to the perceived credibility of the physician; for example one participant recounted, “The doctor did a quick ultrasound and he said everything looked normal but it wasn’t his area, so he wasn’t totally sure”. Later this woman said: “Well, I think everything looks okay but let’s just have another opinion just in case… You’re like, really? Let’s do this right the first time! ”. It is perhaps the language that the physician in

this case used that decreased his credibility, that is saying “he was unsure” and “it wasn’t his area” and thus increased this woman’s uncertainty and frustration.

It did not appear that the gender of the health care provider was relevant to how the women perceived staff attitudes as female and male nurses, physicians and ultrasound technicians were mentioned and characterized positively and negatively.

Social Support and Barriers to Support

Literature suggests that social support is inversely correlated with uncertainty; that is that higher levels of social support correlate to lower levels of uncertainty (Giurgescu et al., 2006; Hui Choi et al., 2012; Mishel 1988). Social support is also positively correlated with preparation, positive interpretation and psychological well being and inversely related to distress (Giurgescu et al., 2006). Social support was frequently cited as a tool used by women experiencing bleeding during pregnancy to either help them cope or help reduce their anxiety and uncertainty.

The principal function of social support is allowing a person to clarify his or her situation through discussion and interaction (Mishel & Braden, 1987). Furthermore, this interaction will help the person interpret and determine the extent of the threat in a specific situation; this occurs by providing information about the situation itself or about resources that may be available for coping with the situation or threat (Mishel, 1988; Mishel & Braden, 1987). Effective social support also serves to reduce uncertainty by interpreting events and providing feedback which allows the person to form a cognitive schema of the event,

thereby reducing the perception of lack of control and encouraging consideration of the positive aspect of a given situation (Mishel & Braden, 1987, 1988). The woman in this excerpt describes her experience of waiting while separated from her husband:

> I always think of the worst scenarios and my husband kind of counteracts that by being more like, "Everything's going to be fine"…"They just did the ultrasound." So he looks more on the brighter side of the picture…So it would have been nice, even to just bounce, you know, things off of him, would have been nice. Or to take my mind off it by talking about something else instead of just sitting there and thinking, the whole scenario through over and over again.

She makes it clear that having her husband with her would have reduced the distress she felt while waiting alone; he could have helped her reframe her view of events, persuade her to focus on the encouraging aspects of the situation, as well as provide a welcome distraction instead of allowing her to ruminate constantly about the bleeding. This also supports the assumption that a solo wait would feel longer and that unoccupied time feels longer then occupied time (Maister, 1985).

Among the women in this study social support reduced distress and uncertainty both directly and indirectly. Directly, social support, particularly from a spouse, provided a calming, compassionate presence that encouraged consideration of the positive aspects of the situation. Yet social support also indirectly reduced uncertainty and distress via the process of information provision, for instance women sought out the advice of friends on what they could

anticipate with respect to pregnancy loss. Women sought information from what they perceived to be credible sources, either women who had experienced bleeding in pregnancy previously or had professional knowledge bleeding in pregnancy. Uncertainty is reduced when the person relies on their support person to affirm beliefs concerning their illness event, in this case bleeding during pregnancy (Mishel & Braden, 1988). Affirmation allows for the exchange of opinions and perspectives of the situation and then having these views respected and confirmed (Mishel & Braden, 1988). Contact with others who have faced the same experience functions to reduce the uncertainty caused by confusion of the experience (Mishel, 1988). One woman recounts how she called a friend who had recently miscarried for advice, "Once I was pretty sure it [a miscarriage] was happening, I knew she could [help]. We're kind of members of a really crappy club together". Given that social support appears to be a potent force in reducing distress, anxiety and uncertainty in women with bleeding during pregnancy, it is disappointing that many barriers to accessing this support were frequently encountered.

Lack of Privacy

Lack of privacy notably increased the distress of waiting, particularly when it came to the waiting room itself. Women resented being on display in view of others when they were experiencing often visible emotions about a very personal and intimate experience. In at least one case the display of visible emotions resulted in other patients asking about the nature of the woman's presenting concern. This further violated a sense of privacy and increased distress.

The chaos of the waiting room itself was also a factor; women indicated that they would have preferred to be away from others in a calmer, quieter environment. When in hospital on another occasion one participant describes the existence of a room separate from the waiting room.

> A separate room that was more serene and calm-looking, for anyone that was experiencing any kind of crisis. It had more sofa-like chairs…pictures on the wall, painted blue or something like that to be more serene, but something like that probably would have been nice to be able to use, just to even initially, like calm down and get a hold of myself because you get yourself so worked up.

Lack of privacy also extended into the emergency department itself. For example, one woman described being assessed in room with curtained walls which allowed other patients to overhear the nature of her presenting concern as well as hear the details of private and intimate medical information. One woman recommends that staff should try "to get them [women] into a private exam room or somewhere that's maybe not as loud or busy because it's such an emotional thing to go through". Loss of privacy in this regard was not universal as some women mentioned being placed in a private area for the initial assessment of their bleeding. What was pervasive however was the women's desire and need for privacy.

The requirement of a wearing a hospital gown was another factor that women mentioned both as an element in the loss of privacy as well as an additional stressor of waiting. Women awaiting diagnosis after abnormal

mammogram reported significant distress as a result of what they characterized as dehumanizing interactions with health care professionals (Thorne et al., 1999). Women in that study reported feeling "degraded" or "humiliated" by interactions such as staff coming in and out of their rooms while the women were half naked, as well as women realizing the amount of staff that had seen their breasts. Being required to wear a hospital gown stripped away more than just clothing; it compounded feelings of vulnerability for women in a time of intense emotion.

The final affront for at least one woman was being deprived of a private place to grieve and process the news of a negative outcome in her pregnancy. This was particularly disturbing for her as she was originally informed by staff that she would have a private room to return to. She indicates this added to her distress and the confusion of the situation.

It is clear that lack of privacy increases distress in the context of waiting; moreover it can be linked to increasing uncertainty of the situation. Cognitive capacity refers to a person's ability to process information and suggests that only a finite amount of information can be processed at one time before information overload occurs and cognitive capacity is surpassed (Mishel, 1988). When a number of cues must be attended to, the complexity of a situation increases, which impedes the development of event familiarity and increases uncertainty (Mishel, 1988). If women must be attuned to many cues, such as those in a busy emergency room waiting room, then this would diminish cognitive capacity and thereby result in increased uncertainty. Reducing these cues or stimuli, such as

allowing women the opportunity to wait in a more private, calmer room would lessen anxiety and possibly also the uncertainty of their situation.

Inadequate Provision of Information and Information Seeking

There was dissatisfaction expressed with the amount of information received in all stages of the experience of bleeding in pregnancy. Sufficient information provision has been identified as an essential component of patient satisfaction; not surprisingly, the more information that is provided, the more satisfied patients are overall (Bjorvell and Stieg, 1991; Krishel & Baraff, 1993; Mowen, Licata, & McPhail, 1993; Thompson et al., 1996). Patients are more satisfied with their emergency room experience when they perceive that they have received clear explanations for procedures and tests as well as discharge instructions (Thompson et al., 1996). Moreover, providing information to patients about the expected emergency room processes, such as the function of the emergency room and the patient evaluation time may result in increased satisfaction with care (Krishel & Baraff, 1993).

Lack of information leads to increased uncertainty as it impedes the construction of a frame of reference (McCormick, 2002; Mishel, 1988). Correspondingly, this knowledge deficit leads women to mobilize coping techniques by direct action of information seeking as a means for reducing uncertainty (Mishel, 1988). This is clearly illustrated by one woman who says, “because I felt like nobody would really tell me much, I Googled everything”. Women sought information from sources including, friends or family members, the internet or other health care providers. Two of these, significant others and

other health care providers are mentioned by Mishel (1988) in her *Uncertainty in Illness* theory. She contends that information that is sought by significant others functions to reduce uncertainty by providing expert information or by interpreting events. This was further elaborated on in the discussion of the role of social support in uncertainty. Moreover, Mishel (1988) offers that health care providers reduce uncertainty by structuring the information. While the internet was not mentioned by Mishel as one of the means of information seeking this is likely due to the fact that the internet was not as widely used in 1988 when she first published her paper. It is now widely used as source of medical information

For instance, more than half of the respondents in a random sample of primary care patients disclosed that they used the internet to search health information (Diaz et al., 2002). Additionally, respondents felt the information they obtained from the internet was either the "same as" or "better than" information from their doctors. Interestingly, use of the internet for medical information was significantly correlated with higher education and higher income. An internet survey was used to establish the reasons for why pregnant women use the internet as a source of health information (Lagan, Sinclair, & Kernohan, 2010). Most women (93.8%) used the internet to supplement information provided by their health professionals. Moreover, 46.5 % of women cited lack of time to ask their health professionals as a reason they sought health information online. Almost half of the respondents (48.6%) reported using the internet as they were dissatisfied with the information they received from their health professional, indicating it was unclear or unsatisfactory. Similarly women in this

study sought information from the internet due to insufficient information provided by their health care providers. For instance, one woman said, " [I] went and looked up all these things on the internet and it's like, just a lot contradictory information. So having a little bit more guidance from the health care provider…"

This lack of accurate information provided by health care professionals is particularly significant as at least one woman indicated that she used her internet research to guide her decision making process on whether or not she should follow up with her family physician after a miscarriage. More specifically, there is no assurance that the information women are receiving from the internet is credible.

McCormick (2002) asserts that not being given adequate information is the most easily rectified case of uncertainty; provided that the information is known and can be confirmed. Therefore, uncertainty could have been lessened had the emergency physicians imparted adequate information on the women. But this assumes that the physicians were in possession of this knowledge, that is that they knew what the bleeding meant for these women. In many of the cases until an ultrasound was performed the emergency physician who could only guess as to what the bleeding meant and what its eventual outcome would be. The physician could not reduce the women's uncertainty if they themselves remained uncertain as to the potential outcome. One woman showed insight into this possibility, she says:

> Either they don't know or they don't want to be the ones to tell me that I'm [miscarrying]…I remember leaving there and thinking, you know what? Maybe they really can't tell me yet.

However, for the women whose pregnancy outcomes were in fact known, being provided information on what to expect would have certainly reduced their distress and uncertainty.

Related to the concept of inadequate provision of information and information seeking is education level. Mishel (1988) asserts that education level affects uncertainty directly and indirectly; directly as those having higher levels of education are able to modify uncertainty more rapidly, requiring less time to construct the meaning of events than those with less education. Moreover, indirectly, education can lower uncertainty by to broadening the knowledge base giving meaning and context to the event. All of the women in this study expressed uncertainty and distress and had at least a university education. One participant said:

> If there's recognition that a lot of people coming in aren't going to be as resourced as I happened to be that day… that's where I get concerned and that if they could be aware of that in treating people, that would be really helpful, I think.

Although it was not specifically addressed by this study, the consideration that women with lower levels of education may have higher levels of distress and uncertainty related to their bleeding requires acknowledgment.

Hindsight

Whether or not women would return to the emergency room for evaluation of bleeding during pregnancy was mixed and varied as a function of their perception of the value of the visit, their perception of the management of their concern and the identified outcome of their bleeding.

It seems that some women would choose to return to the emergency room regardless of their satisfaction or dissatisfaction of their experience if they thought that it could offer the answers they were seeking. That is, some women would return to the emergency room in hopes of lessening or eliminating the uncertainty of bleeding during pregnancy. While other women indicated that they would not return to the emergency if they found themselves in a similar situation; perhaps they believe that the uncertainty of their situation at that point would already be reduced as they would be familiar with the symptom pattern. However, if the concept of previous experience is any indication, bleeding in a prior pregnancy does not appear to reduce anxiety and uncertainty of bleeding in a subsequent pregnancy. It is possible that the women who would choose not to return to the emergency room had a more overall discouraging visit and therefore would not return for that reason. Or again perhaps they felt that the emergency room visit did little to relieve their uncertainty. In either case, the perception of the overall experience in terms of satisfaction or dissatisfaction requires further exploration.

Chapter Six

Limitations, Implications, Recommendations for Future Research

Limitations

Potential limitations including study design, recruitment challenges and researcher challenges will be presented next.

Study design.

The sample size for the study was appropriate for an initial exploration of the experience of bleeding during pregnancy; however, in order to better understand the experience of bleeding during pregnancy it would have been valuable to have a larger sample of women. It is possible that due to the small sample size all concepts related to bleeding during early pregnancy were not fully described. As indicated earlier, the aim of choosing participants purposively did not prove achievable and women in this group were relatively homogenous with respect to age, marital status and education level. Conversely, there was diversity among women with respect to their obstetrical history, including gravidity and pregnancy outcome. However, it would be worthwhile to determine how the concept of uncertainty and waiting may have been shaped if women were without a source of social support or if they were not as well educated or resourceful as these women. For instance, talking with inner city women about their experiences of bleeding during pregnancy would likely provide a different description then women from the current demographic. Moreover, exploring a wider range of obstetrical backgrounds including women with recurrent pregnancy loss or those

with no successful pregnancies would add to the richness of the description of this experience.

Women who agree to participate in studies may have a different experience of bleeding then women who would not volunteer to be interviewed, however this is inherent in the self- referral recruitment method; ultimately only women who volunteer to participate will participate. In addition, the researcher assumes that the woman who volunteered to participate had valuable input as bleeding during pregnancy was a significant event in their lives, however the experience may have been related differently if the bleeding or pregnancy was not as meaningful for a particular woman. Furthermore, as all of the participants were Caucasian and spoke English the impact that culture may have had on shaping the experience of bleeding remains unknown. Not all the women that volunteered were within the time frame of 16 weeks after their episode of bleeding; therefore the perceptions of their experience may have changed over time and their recall of the events may not have been as clear as if they had been interviewed sooner. However, the researcher asserts that at least for this subset of women, bleeding during pregnancy was significant enough of an event that despite the passage of time they were able to relay the essence of their experience. Notwithstanding, it would have been worthwhile to talk with women while they were actually having the experience of bleeding for instance while they were in the emergency department. This would allow the woman to immediately share what she is thinking about and feeling while she waits.

Recruitment challenges.

Several factors likely contributed to a lack of sufficient interest in volunteering to participate in this study and may be attributed to researcher oversight, participant characteristics, and /or recruitment site factors.

Firstly, despite the attempt at strategic placement, perhaps the recruitment posters were not clearly visible to women who were waiting. Furthermore, it is possible that it was not clear from the posters which women the researcher wished to interview. For instance, perhaps women who experienced bleeding but continued on in their pregnancies assumed that the researcher was only interested in talking to women who had miscarried. And conversely, women who miscarried may have assumed that the researcher was looking for women who remained pregnant. Or perhaps given the intimate nature of the subject material women were simply not interested in sharing very personal and distressing emotions. Moreover, it is likely that women who did miscarry were too self-focused to notice posters or to consider participating even if they were aware of them.

One probable contributor to recruitment difficulties was the reality of multiple demands on a woman's time, particularly family and career obligations and simply feeling as if they just did not have time to participate. The logistics of participating in an interview, such as finding a suitable meeting place and time and arranging care of other children may have been overwhelming.

It is also likely that there was lack of staff interest in directing women to the posters or providing women an invitation to participate. Handouts and posters alone did not serve as sufficient motivators for women to self-refer to participate.

The lack of staff involvement may have been due to apathy or perhaps staff felt threatened at the possibility of the study identifying any practice issues.

If this study were to be replicated it would be beneficial to have the researcher located within the emergency department and identify potential women while they are waiting and determine if they are interested in participating in the study while they wait. Although interestingly this may shape their experience as they are no longer just sitting and waiting, they are talking about how they feel and the researcher may be a much needed distraction. Recruitment efforts could also be improved if there was more support for the project from on site staff to help identify women who may be interested in participating in the study.

Researcher challenges.

During the course of the study, the researcher became pregnant. As the pregnancy progressed, the researcher was sensitive to the possibility that those women who had experienced a pregnancy loss may not wish to be interviewed by a visibly pregnant woman. This notion caused the researcher anxiety and uncertainty about how she would be received by the participants. The researcher endeavored to not overtly display the pregnancy and thankfully if women who were interviewed noticed the pregnancy they did not comment or appear uncomfortable. A possible limitation is that the researcher had to withdraw from active recruitment of participants due to medical reasons related to the pregnancy. When the researcher did return to active data collection again a lapse occurred due to balancing family and career obligations. Namely, the researcher had to complete several hundred practical hours for her nurse practitioner licensure,

while maintaining a household and caring for a minor child. Thus, time from data collection to analysis was much longer than originally anticipated and this time lapse could be viewed as a limitation. On the other hand, the time lapse from the resulting pregnancy and post partum period did provide the researcher with a unique perspective and insight into the experiences of the women making it easier to understand and empathize with some of their concerns. The researcher asserts that having a child during the course of the study allowed her to see the evolution of the experiences of women both with children and without.

Implications

Patients' satisfaction with their care in the emergency room is multifaceted; while decreasing wait times may lead to increased satisfaction with care, in most cases this is simply not feasible by virtue of limited resources. Interestingly, perceived waiting time is significantly correlated with overall patient satisfaction while actual waiting time is not (Thompson et al., 1996). Although chronologically the participants had a relatively short waiting time prior to physician assessment, with a mean of 38 minutes, and a median 29 minutes, the percentage of patients who described their emergency visit as excellent remained reasonably constant regardless of the time to initial physician assessment even when it was more than 75 minutes. Similarly, Mowen et al. (1993) reported that patients who believed they had been given information on their expected wait time were more satisfied then those who did not believe they were given this information. While these studies focused on the concept of patient satisfaction and not specifically distress or uncertainty it seems probable that patient distress is

inversely related to patient satisfaction. That is, that more satisfied patients would be less distressed.

The quandary may become, 'Do satisfied patients perceive their care as better or does better care result in more satisfied patients'? Realistically the distinction is not that important, provided patients are satisfied and they receive high-quality care. In summation, in order to generate the most satisfied patients it is imperative to meet or exceed their expectations. It is the patients' perception of their health care encounter that will dictate how satisfied they are with the care they received. Constructive implications for improving the care of women experiencing bleeding during early pregnancy at the level of nursing education, nursing practice and at a policy level will be presented next.

Nursing education.

There may be a tendency for students and novice nurses to focus on more practical skills, such as initiating intravenous lines; however, nursing education should reinforce core nursing values and standards. Nursing educators should ensure that students are practising within the foundations of ethical and competent nursing practice in accordance with the following documents: *Code of Ethics for Registered Nurses* and *Practice Standards for Regulated Members* (Canadian Nurses Association, 2008; College and Association of Registered Nurses of Alberta, [CARNA] 2013). More specifically, for women with bleeding during pregnancy the principles of protecting and promoting a client's right to respect, dignity and privacy are particularly important. Nursing educators should also familiarize students with the concept of moral distress, for instance, when a nurse

would prefer to remain with a patient during an emotional time such as bleeding during pregnancy but are instead constrained by other demands on their time. Opportunities for discourse in how these feelings may arise and what can be done about them should be provided.

Nursing practice.

Present an attitude of compassion, comfort and understanding.

Women described how modest gestures provided a gentleness and comfort that they desperately needed. For instance, one woman described feeling comforted and cared for when a nurse brought her a hot blanket as she was feeling cold. Nurses should ensure that they are presenting an attitude of compassion, comfort and understanding. One woman illustrated this by saying, "there was some comfort in knowing that my opinion and my feeling and what I might be going through in that experience was important". Another woman offered the following advice to her health care providers:

> Treat every miscarriage that they are looking at, or might be looking at, they have to treat it like it's their daughter or themselves. It's probably easy to get kind of blasé about it in the medical world, but we're not going through it like they are. It's real to us, so if they could just be sensitive about it.

Likewise one participant requested the following, "making the patients feel like what they're going through is significant and that they're being heard and looked at and treated, like they should be…emotionally and physically just going through the right steps, I guess you could say".

Be present.

For some women, a warm and gentle approach while essential, may only offer partial comfort. For example, one participant articulated that although the nurses were friendly, they lacked the time to just be present with her. She said, "There's no one to just sit and chat with you…no one to just hang out for 40 minutes". This suggests that nurses can offer valuable service to women by simply being present, perhaps allowing for discussion or distraction.

Regrettably, this is often not feasible due to the nature of the practice setting of the emergency room. In an ethnographic study of staff and women with early miscarriage in a hospital gynecology unit, Murphy & Merrell (2009) discovered discordance between how nurses would like to practice and what was actually possible to accomplish in their work day. For instance, nurses recognized miscarriage as an emotionally turbulent time, yet were often unable to meet women's emotional needs due to time constraints; saying, "I know it sounds awful but we haven't, we haven't got time to sit and discuss things" (Murphy & Merrell, 2009, p. 1587).

Pregnancy adds a unique dimension.

It is imperative that staff be attentive of the individual meaning that each woman attaches to her pregnancy and that being pregnant adds a unique dimension to waiting. The meaning of her pregnancy is much more of a potent factor in how the women will react to its potential loss then other variables such as gestational age. This is essential for nurses to understand; for instance a woman who is six weeks pregnant may have a more powerful emotional reaction to

bleeding in her pregnancy and its potential loss then a woman who is 14 weeks of gestational age. There is no clear definition of when that pregnancy becomes a child for that woman. This woman poignantly illustrated this idea saying:

> One of the things that I understand about the medical system is it's not always of understanding about the impact of miscarriage on people and I think that it's a pretty emotional one for most women that go through it, on whatever stage they are at, whatever, it's an emotional experience and most women don't view their babies as babies only when they're 12 weeks.

Nurses should be aware of how their own beliefs about pregnancy may shape their behavior and be cognizant to present an objective and non-biased approach to all patients.

Avoid negative responses to uncertainty.

Nurses should aim to avoid common negative reactions to a woman's uncertainty as outlined by Sorenson (1990). Foremost, it is important for nurses to be conscious that uncertainty exists and appreciate how distressing these uncertainties may be for women. This is especially significant for women experiencing bleeding during pregnancy; nurses must recognize that these women are essentially trapped in a mental limbo. Until the uncertainty of their situation is resolved, women don't know whether to be mournful and grieve or be relieved and grateful. Moreover, nurses should aim to proceed in a concerned, sensitive and interested manner and encourage discussion and expression of the uncertainties women may be feeling. This should help prevent women from

feeling as if their health care providers are intolerant and indifferent to their uncertainty.

Promote and accommodate social support.

It is recommended that all staff be educated on the importance of adequate social support and be encouraged to remove any barriers to effective social support. Women should be allowed at least one person to accompany them while they are waiting and spouses or support persons should be allowed them to participate to the point that the woman is comfortable with their company. For instance, comfort could be promoted by allowing a spouse to be present during ultrasound examination, particularly if any news on the diagnosis will be shared.

Ensure adequate provision of information.

Women expressed dissatisfaction with the amount of information they received in all stages of their experience of bleeding in pregnancy; inadequate provision of information lead to increased uncertainty. Not surprisingly, patients are more satisfied with their emergency room experience when they perceive that they have received clear explanations for procedures and tests as well as discharge instructions (Thompson et al., 1996).

The experience of waiting could be ameliorated by simply providing patients more information about what is known. This should start at the entry point to the emergency department, triage. For instance, although only anecdotally, it seems as though women are more understanding of waiting to be assessed by a physician if it is explained to them that they are awaiting a special kind of bed for pregnant women with this particular issue and that it is currently

occupied. Perhaps they identify with the other woman currently utilizing that bed in their same situation, or at least appreciate that they are waiting, or competing for a bed as some may see it, with other women with the same issue, not with all the patients that are in the waiting room. Recalling women from the waiting room to the triage desk for reassessment assures nurses that the patient's status hasn't changed and can also provide reassurance to women that they are being cared for and that they have not been forgotten.

Moreover, nurses can explain to women what they can expect in their visit, for instance that they may have their blood drawn and the purpose this serves. Or by explaining that women will be asked to change into a hospital gown as this facilitates the physical exam and then further detailing what the physical exam will entail. Nurses should encourage discussion with women about what they know, what they don't know and what they want to know, thereby facilitating effective communication, not simply assuming what a woman knows or would want to know.

While it may not be within the nurse's scope of practice to provide women with information with respect to the viability of a woman's pregnancy, it is the nurse's responsibility to insure that prior to discharge, women are comfortable with the level of information they have received about what to expect and the plan for follow up care. Furthermore, it is the nurse's duty to advocate to the physician on the patient's behalf if there are lingering questions or doubts.

Despite the anguish of losing a pregnancy, some women reveal that the uncertainty and false hope they were provided was equally if not more distressing.

For this reason if the fate of the pregnancy is known, sensitive but frank language should be used. Any removal of ambiguity and dissipation of uncertainty should serve to reduce women's distress with waiting.

Policy level.

Revise visitor policies.

While physical space is often at a premium in the emergency room, institutional visitor policies should be revised to ensure they allow and support the presence of spouses, friends or family members, especially in times of crisis. For instance, it is important to allow at least one person to accompany a women experiencing bleeding. Furthermore, it would not be uncommon for a pregnant woman to be responsible for the care of another minor child and have a working spouse when presenting to the emergency department. Therefore, visitor policies should be flexible and reflect the awareness of potential family obligations such as allowing a minor child to accompany her/his mother to non-invasive diagnostics procedures such as ultrasound exam when there is no option for alternate care.

Demystify the emergency room process.

Novelty and complexity within the health care environment hinder the development of event familiarity; in turn amplifying uncertainty (Mishel, 1988). A confusing physical layout or difficulty in deciphering the delivery system will also impede the encounter and increase uncertainty (Bopp, 1989). Bopp (1989) advocates designing service in a manner that ensures that patient flow is systematic and well organized, which in turn promotes a sense of confidence in

the care patients receive. Therefore, demystifying the emergency room process, for instance explaining the priority system for being assessed for those in the waiting room and providing women with a flow sheet documenting how their visit will proceed may serve to reduce uncertainty by diminishing the complexity of the emergency room process.

Privacy.

Given the intimate nature of this experience, women undergoing evaluation for bleeding in pregnancy should be placed in a private room with walls and a door when possible. This allows for a more confidential discussion of intimate details such as the course of vaginal bleeding, whether it was associated with intercourse and the need for a pelvic examination. This privacy is also important for women to express any emotions they may be feeling as a result of their bleeding such as crying or grieving with a partner. Moreover, the use of hospital gowns should be reserved for imminent physical examination and then women should be allowed to change back into their regular clothing afterwards. The distress and uncertainty of the experience of waiting with bleeding during pregnancy can be reduced by supporting a woman's right to privacy, dignity and respect.

Restructure the waiting area.

Restructuring the waiting area could reduce distress and uncertainty by supporting and facilitating cognitive capacity. Mishel (1988) warns that cognitive capacity is disturbed by demands on attentional capacity and hence results in increased uncertainty. Moreover, Mishel (1988) proposes that if danger is

perceived within the health environment cognitive efficiency is even further weakened. Therefore, the chaos of a busy emergency waiting room is not compatible with preserving cognitive capacity. Instead a more private, calm and serene waiting room may help to stabilize cognitive capacity and thereby reduce uncertainty. Restructuring of the waiting area is likely not realistic in the current health care climate, however allowing women to briefly leave the waiting area to fulfill physical needs such as accessing food and water or taking a short walk for emotional release or to calm down may reduce some of the unpleasantness of waiting.

Use of bedside ultrasound.

Advances in technology have led to the use of "portable" or "bedside ultrasounds". Some physicians will use the bedside ultrasound to evaluate woman with bleeding during early pregnancy, to get a "quick glimpse" as to what may be going on. For instance, locating fetal heart motion is a reassuring sign, as if it is visualized, 95% of pregnancies will continue to live birth (Coppola & Coppola, 2003, Snell, 2009). However, the ability to use this tool relates to the gestational age and the comfort level of the physician. Invariably, a formal ultrasound will still be performed to evaluate and confirm the findings of the bedside ultrasound. Interestingly, informal discussion between the researcher and physician colleagues exposed some contention over the use and purpose of the bedside ultrasound. There was variability in the use of the bedside ultrasound from "never used" to "always used" to evaluate bleeding in the early pregnant woman. Moreover, some physicians indicated that the bedside ultrasound was only

intended to diagnose or exclude ectopic pregnancy, and not to determine presence of fetal heart movement or provide reassurance to the woman as to the status of the pregnancy.

It was the researcher's assumption that the use of the bedside ultrasound would be a valuable tool allowing a quick assessment of the viability of the pregnancy, possibly providing reassurance and dissipating some uncertainty and distress while awaiting formal ultrasound evaluation. However, the one woman in this study who was assessed at the bedside with a portable ultrasound machine did not agree. Interestingly, the woman indicated that this assessment tool did nothing to relieve her uncertainty, and instead she said it was "frustrating because I just wanted a concrete answer right then...what's the point in doing this one if you just have to do another one anyway?"

In addition, women may experience increased distress, especially if the beside ultrasound does not reveal fetal heart motion, realizing that their pregnancy is no longer viable. It is difficult to discern without further research in this area, if the uncertainty of the bleeding and waiting is more intolerable then having a negative outcome such as a non viable pregnancy, and perhaps the use of bedside ultrasound could be helpful in illustrating this.

Establish an early pregnancy assessment program.

The current practice model for evaluating women with bleeding during pregnancy results in considerable uncertainty. Moreover, research indicates that it can result in prolonged wait times, inappropriate use of resources and the lack of clear treatment and follow up plans (O'Rourke and Wood, 2009). The early

pregnancy assessment program (EPAP) is the standard of care in the United Kingdom (UK) for women experiencing complications in early pregnancy (Condous, 2008; O'Rourke & Wood, 2009; Tunde-Byass & Cheung, 2009). However, the EPAP model is uncommon in Canada, and is not used in the province of Alberta. Condous (2008) argues that the current practice model is "antiquated" and that the (EPAP) model functions to streamline the management of early pregnancy complications and "reduce the impact of early pregnancy problems on an already overburdened public health-care system" (p.2). Evidence has established that EPAP's result in increased patient satisfaction, reduced length of hospital stay, decreased emergency room presentations for repeat assessment and even direct cost savings (Bigrigg & Read, 1991; Tunde-Byass & Cheung, 2009). In short, the EPAP model functions to fast track women who do not require urgent medical intervention and provides sensitive and timely access to assessment, information, and follow-up care (Indig, Warner, & Saxton, 2011).

At least two women alluded to desiring a program similar to an EPAP. For instance one woman said, **"**If there could be an early pregnancy centre you could go to, like in a perfect world… and they're kind of sensitive to what's going on, they don't have to worry about the diabetic and the broken bones". Similarly another woman submitted that she would have preferred,

> An area designated for this kind of stuff [pregnant and bleeding] …an area where it's people maybe going through the same thing or even like, just something similar…if you went to a place where, albeit there might be

other pregnant women, there might be other women that are miscarrying and it's more geared towards, you know, the women's needs.

Seminal research assessing the efficiency of the EPAP model in the care of women experiencing bleeding or pain in early pregnancy demonstrated improved quality of care and savings in terms of financial and staff resources (Bigrigg & Read, 1991). In fact, the EPAP model resulted in a 28 to 44 % reduction in unnecessary admission to hospital while another 20% of women had a reduced length of hospital stay (Bigrigg & Read, 1991). Moreover, the calculated savings associated with operating the EPAP was between £95 000 and £120 000 in one year (Bigrigg & Read, 1991). Although much of the literature surrounding EPAP services is from the UK and Australia, there are some, albeit few, articles that describe the use of EPAP's in Canada.

The EPAP model was undertaken at a Toronto hospital in 2005 with the objective of providing women with early pregnancy complications "immediate, efficient, and compassionate care with a one-stop approach" (Tunde-Byass & Cheung, 2009, p.844). The EPAP was designed to offer prompt diagnosis, options for management, bereavement counseling and follow-up for women experiencing complications of early pregnancy. Chart review yielded that the number of patients presenting to the ER with diagnoses of miscarriage, early pregnancy hemorrhage and ectopic pregnancy was not significantly changed before and after opening of the EPAP. On the other hand, the implementation of the EPAP correlated with a significant decrease in the amount of repeat assessments for these above mentioned diagnoses. The authors speculate that a limitation in the

hours of operation of EPAP could have impacted the amount of women still presenting to the ER. In this study the "value" of the EPAP in terms of pregnancy complications and the number of emergency room visits was evaluated; the researcher asserts that there is also a need to assess the value of the EPAP in terms of women's satisfaction, distress and uncertainty.

EPAP's can improve outcomes for patients and the efficiency of the health care system and they also introduce a role for nurse practitioners (NP). The assessment and diagnosis of bleeding during early pregnancy falls within the legislated scope of practice for Alberta nurse practitioners. That being, that NP's have a broad and autonomous scope of practice that allows them to perform comprehensive health assessments, diagnose health conditions, order and interpret laboratory and diagnostic tests, prescribe drugs, perform invasive and non-invasive procedures, monitor outcomes, provide consultations and referrals as well as provide ongoing care (CARNA, 2011). Examples of successfully run NP led EPAP's convincingly demonstrate that specially trained NP's are competent and capable of leading EPAP services are reported in the literature (Fox, Savage, Evans & Moore, 1999; Webster-Bain, 2011). Perhaps, NP's are best equipped to lead EPAP services due to their rooted position in nursing centered care and the ability to provide individualized and holistic care. A change in practice is clearly warranted, with NP's primed and ready to care for these women in a way that is so obviously lacking.

Recommendations for Future Research

While the focus of this study was describing the experiences of women with bleeding during early pregnancy who were waiting in the emergency department, intriguingly the inclusion of a woman who had not had her assessment in the emergency room yielded relatively similar concerns to those raised by the other women. This lends support to the idea that the essence of the experience of bleeding in pregnancy is a function of waiting with uncertainty, and the emergency waiting room is a only the arena that houses contributory factors that increase or decrease uncertainty and resultant distress. Therefore, further inquiry into the experience of waiting with bleeding during pregnancy should be explored in other settings and with other health care professionals including obstetricians, family physicians, nurses and midwives. Moreover, further exploration of uncertainty and waiting while bleeding in pregnancy among a larger sample of women should be considered. This should consist of purposive sampling to achieve a less homogenous group of women and specifically include single or unattached women, women within all levels of education and socioeconomic status as well as women with cultural diversity. It would also be worthwhile to talk with women while they are actually experiencing bleeding, for instance to sit with women while they are waiting and talk with them about what they are thinking and feeling as they experience it.

Replicating Clauson's (1996) investigation of women experiencing bleeding during early pregnancy rather than high risk hospitalized antepartum women should be considered. This could provide a further understanding of how

women perceive the uncertainty and stress related to bleeding in pregnancy, as well as, explore how factors such as gravidity, level of social support, maternal age, gestational age, and length of wait time relate to stress and uncertainty.

Although an exhaustive literature search was not performed it is evident that the amount of evidence on personal intuition or "knowing" in bleeding during pregnancy was limited and this could guide future inquiry into the experience of bleeding during pregnancy. Similarly, further exploring the concept of "false hope" and how it relates to uncertainty and bleeding in pregnancy should be contemplated. In addition, future research should be directed towards the utility of interventions designed to reduce the distress and anxiety of waiting and uncertainty. For instance, the positive reappraisal coping statements or positive mood statements as utilized by Lancastle and Boivin (2008) for women awaiting pregnancy test after IVF embryo transfer.

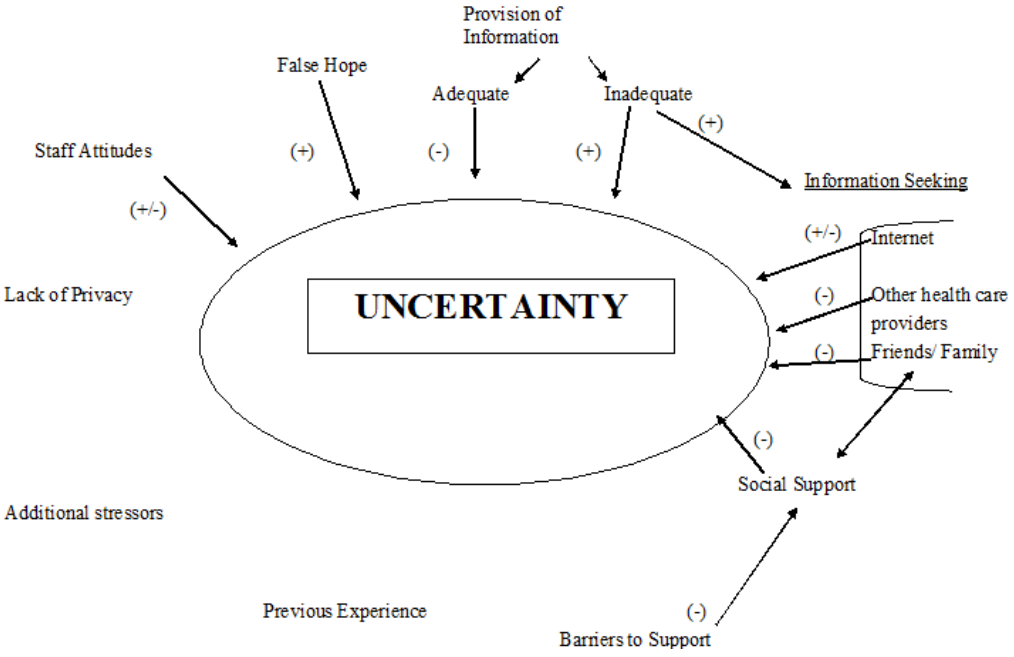
Further examining the relationship of staff attitudes and the experience of waiting with bleeding during pregnancy should be undertaken, including scrutiny into the existence of a true dichotomy with respect to the descriptive characteristics ascribed to nurses versus physicians by women with bleeding during pregnancy. Finally, it would be worthwhile to explore factors that are associated with levels of satisfaction among a cohort of women with bleeding in pregnancy with the goal of yielding concrete recommendations for improving their satisfaction with care.

Chapter Seven

Conclusion

Through the use of an interpretive descriptive design and unstructured interviews this study sought to understand how women with bleeding in early pregnancy described their experience of waiting in the emergency department. The essence of the experience of waiting while pregnant with bleeding can be expressed as the interplay between uncertainty and external factors. How these factors seem to relate to one another is depicted through the use of the model included below as Figure 1.

Figure 1. Concept Map: Interplay between uncertainty and mediating factors



Most importantly, the interviews supported that uncertainty is central to waiting while bleeding in early pregnancy. Women identified factors that served to increase and reduce their uncertainty while waiting, as well as factors which resulted in additional strain on their experience of waiting. For instance, inadequate provision of information and false hope led to increased uncertainty while adequate provision of information and social support were associated with reduced uncertainty. Fascinatingly, information seeking and staff attitude had an equivocal effect on uncertainty among women and was related to the adequacy of the information and the perception of staff attitudes. Future exploration of the experience of bleeding during early pregnancy could be used to build upon the concepts introduced in this model. Discussion was provided which related these concepts to current literature. Moreover, the existence of mediating factors and their effect on shaping the women's experiences of bleeding during pregnancy provides implications for nursing education, nursing practice and policy. For instance, ensuring adequate provision of information, promoting privacy and social support, demystifying the emergency room process, and presenting support for an early pregnancy assessment program.

Finally, suggestions for future research were offered. These included further exploration of uncertainty and waiting while bleeding in pregnancy, perhaps focusing on the relation of other variables such as gravidity, level of social support, maternal age, gestational age, and length of wait time and how these relate to distress and uncertainty, as well as, the utility of interventions designed to reduce distress and anxiety of waiting and uncertainty.

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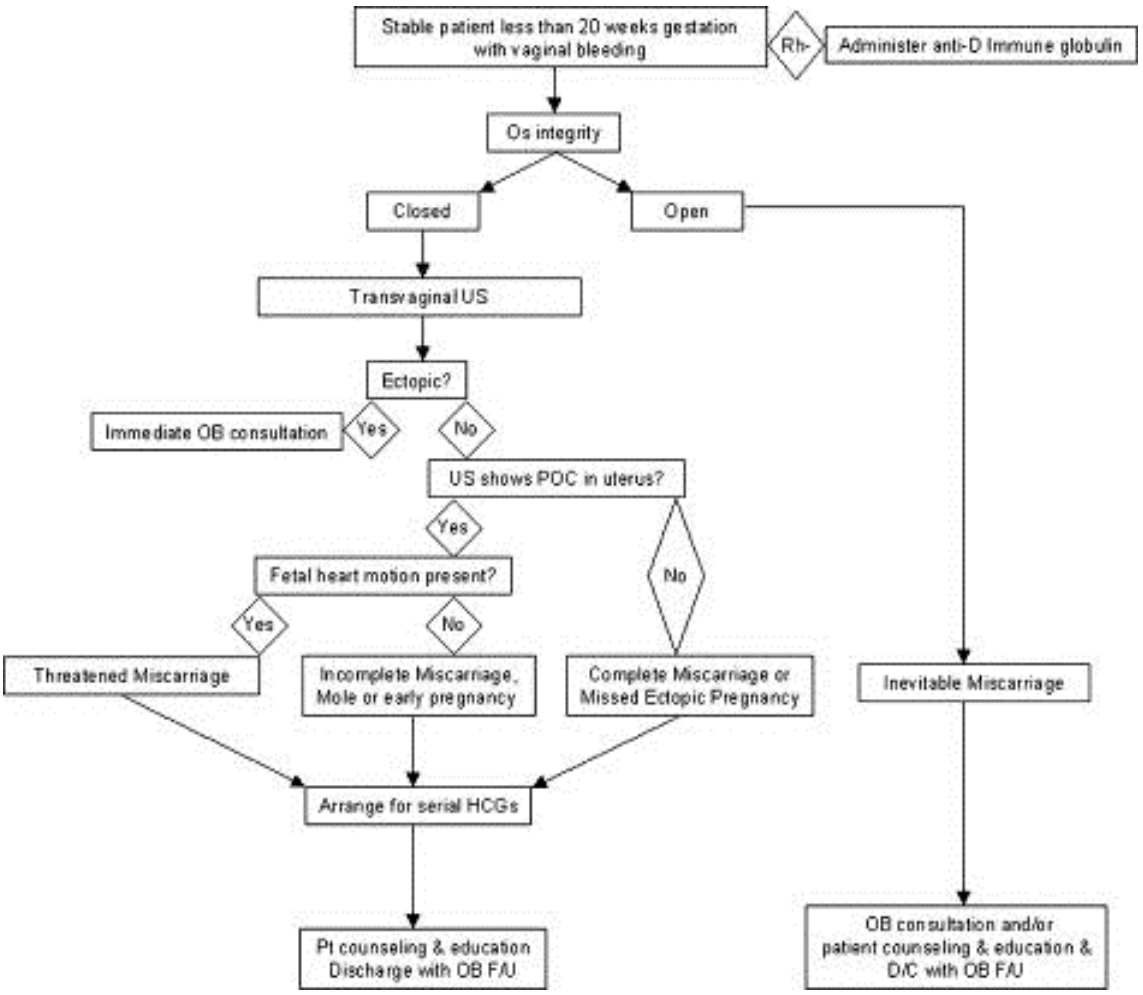
Appendix A

Algorithm for Management of Bleeding During Early Pregnancy



Rh- (Rhesus factor negative), OB(Obstetric), US (Ultrasound), POC (Products of conception), F/U (Follow-up), D/C (Discharge)

Adapted from Figure 2: Algorithm for management of complications of pregnancy (Coppola & Coppola, 2003).

Appendix B

Recruitment Poster

The Experience of Going to an Emergency Room with Bleeding During Pregnancy

Are you pregnant? Having vaginal bleeding?

You are invited to take part in a study to talk about this experience. About 1 in 5 women will have bleeding during their pregnancies. This can be a time of great worry. Women sometimes go to an emergency room to find out what is happening with their pregnancy. We want to better understand what you were thinking and feeling while you were waiting.

If you are interested in being in this study I will ask you to take part in a private interview to take place at a later date that is convenient for you. For more information please contact:

Jaycee Commance, RN Phone (780) 492-8232

Email: commance@ualberta.ca

780-492-8232 commance@ualberta
780-492-8232 commance@ualberta
780-492-8232 commance@ualberta
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Appendix C

Staff Memo

Memorandum

To: Emergency Department Staff

CC:

From:

Date:

Re: Research Study

I have been granted approval to initiate recruitment for my thesis project "*The Experience of Waiting Among Women with Vaginal Bleeding During Early Pregnancy"* at the University of Alberta Hospital Emergency Department.

The purpose of this research project is to understand how pregnant women with vaginal bleeding perceive waiting and uncertainty in the emergency department. I will be asking women who are interested to participate to take part in a private interview and share with me about what they were thinking and feeling while they were waiting.

It is my hope that women will self-refer to participate in my study. In this way you will not be expected to participate in recruitment, nor know any of the details of the study. If you are a triage nurse or working in a patient care area where women with bleeding during pregnancy may present, you may choose to direct women to the poster.

If patients have questions about the study, please direct them to contact me. You can assure patients that participating or not participating will not affect their care in any way and that no one will even know if they chose to take part.

If you have any questions about the current study, please feel free to contact either me, Jaycee Commance at 780-492-8232 or commance@ualberta.ca or my study supervisor Dr. Beverley O'Brien at 780-492-8232 or beverley.obrien@ualberta.ca

Thank you for your time.

Jaycee Commance, BSN, (MN Candidate)
Faculty of Nursing, University of Alberta
5-270 A, Edmonton Clinic Health Academy

Appendix D

Invitation to Participate

THE EXPERIENCE OF GOING TO AN EMERGENCY ROOM WITH BLEEDING DURING PREGNANCY

Why am I being asked to take part in this research study?

You are being asked to participate in this study because you are or were pregnant and went to the emergency room at least once because of bleeding during your pregnancy.

About 1 in 5 women will have bleeding during their pregnancies. This can be a time of great uncertainty, stress and worry. Women sometimes go to an emergency room to find out what is happening with their pregnancy and may not be able to get that information as quickly as they want it. We want to better understand what you were thinking and feeling while you were waiting.

What is the reason for doing the study?

The purpose of this study is to better understand what waiting is like for women who experience vaginal bleeding during pregnancy. This information will help us to understand what you were thinking and feeling so we can provide better care to women. This study is part of a master's thesis.

What will I be asked to do?

If you agree be in the study you will be asked to talk about your time in the emergency room. The talk will take place in a private space and will last between 45 minutes and one hour. If it is easier we can talk on the telephone. Our talk will be recorded and I will take notes to make sure that I heard everything that you said.

If you are interested in being in this study I will ask you to take part in a private interview to take place at a later date that is convenient for you.

For more information please contact:

Jaycee Commance, RN Phone (780)492-8232
Email: commance@ualberta.ca

Appendix E

Participant Consent Form

PARTICIPANT CONSENT FORM

Title of Study: The experience of waiting among women with vaginal bleeding during early pregnancy

Principal Investigators:
Jaycee Commance, RN 780-492-8232
Dr. Beverley O'Brien 780-492-8232

Why am I being asked to take part in this research study?
You are being asked to participate in this study because you are or were pregnant and went to the emergency room at least once because of bleeding during your pregnancy.

About 1 in 5 women will have bleeding during their pregnancies. This can be a time of great uncertainty, stress and worry. Women sometimes go to an emergency room to find out what is happening with their pregnancy and may not be able to get that information as quickly as they want it. We want to better understand what you were thinking and feeling while you were waiting.

(Before you make a decision one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.)

What is the reason for doing the study?
The purpose of this study is to better understand what waiting is like for women who experience vaginal bleeding during pregnancy. This information will help us to understand what you were thinking and feeling so we can provide better care to women. This study is part of a master's thesis.

What will I be asked to do?
If you agree be in the study you will be asked to talk about your time in the emergency room. The talk will take place in a private space and will last between 45 minutes and one hour. If it is easier we can talk on the telephone. Our talk will be recorded and I will take notes to make sure that I heard everything that you said. After our talk I might contact you one more time to see if you want to take part in a second talk.

What are the risks and discomforts? No harm should come to you for taking part in this study but you may feel sad or upset when talking about your pregnancy. If you need it we can refer you to a counselor to further talk about your feelings. It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?
You are not expected to get any benefit from being in this research study. This study may give you the opportunity to talk about a stressful time. What you say may improve the care for other women.

Do I have to take part in the study? You do not have to take part in this study. Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the care or treatment that you are entitled to.

Can my participation in the study end early?
You can change your mind about participating at any time. If you feel uncomfortable or upset during the interview you can stop the study just by saying so. However, if you withdraw from the study once your data has been analyzed it will not to possible to remove what you have said.

What will it cost me to participate?
There will be no direct costs for you to take part in the study, however if we have an interview in a place that has pay parking you would have to pay for parking.

Will my information be kept private?
No one will know you decided to be in this study unless you tell them. Anything you say will be kept private. I will not use your name when I write about this study.
The results of this study will be used in my master's thesis and may be presented at meetings and will be published in scholarly journal. It will not be possible to know who you are by reading these reports.

Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your health information is kept private.

During research studies it is important that the data we get is accurate. For this reason your data, including your name, may be looked at by people from the University of Alberta or HREB.

By signing this consent form you are saying it is okay for the study staff to collect, use and disclose information about you as described above.

After the study is done, we will still need to securely store your data that was collected as part of the study. At the University of Alberta, we keep data stored

for 5 years after the end of the study. What you say will be stored in a locked cupboard.

If you leave the study, we will not collect new information about you, but we will need to keep the data that we have already collected.

What if I have questions?
If you have any questions about the research now or later, please contact

Jaycee Commance, RN	Phone number 780-492-8232
Beverley O'Brien, PhD	Phone number 780-492-8232

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT

Title of Study: The experience of waiting among women with vaginal bleeding during early pregnancy

Principal Investigator(s):	**Jaycee Commance, RN**	**780-492-8232**
	Dr. Beverley O'Brien	**780-492-8232**

Do you understand that you have been asked to be in a research study?

Have you read and received a copy of the attached Information Sheet?

Do you understand the benefits and risks involved in taking part in this research study?

Have you had an opportunity to ask questions and discuss this study?

Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your future medical care?

Has the issue of confidentiality been explained to you?

Do you understand who will have access to your records, including personally identifiable health information?

Do you want the investigator(s) to inform your family doctor that you are participating in this research study? If so, give his/her name

_____

Who explained this study to you?

_____

I agree to take part in this study:

Signature of Research Participant _____

(Printed Name) _____
Date:_____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.
Signature of Investigator or Designee_____
Date _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix F

Demographic Information

1. What year were you born? _ _ _ _
2. What is the highest level of school you have completed?
    - Some high school
    - High school/GED
    - Some college
    - Diploma/trade certificate
    - Bachelor's degree
    - Master's degree
    - Doctoral degree
3. What is your occupation? _____
4. What is your marital status?
    - Single, never married
    - Common law
    - Married
    - Separated
    - Divorced
    - Widowed
5. Obstetrical history
    - Any prior pregnancies?_____
    - If so what were the outcomes of these pregnancies? (I.e. living child, miscarriage, abortion)_____

Note: These questions were answered at the start of the interview by having participants self-complete as a questionnaire or instead were asked in the interview.

Appendix G

Interview Guide

Main Question

Tell me about when you first discovered you were bleeding, what was the experience of waiting like for you?

Prompts

What was it like to come to an emergency room, tell me a little about that?

Tell me about any support you received? Wish you had received?

Was there anything that made this experience better for you? Worse?

Have you ever experienced anything like that before?

What would your advice to others be?