# Navigating early pregnancy loss within Ontario's healthcare system: A qualitative exploratory study of the experiences of midwifery clients and midwives

by

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# **Author's Declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

#### **Abstract**

Background: Miscarriage occurs in approximately 25% of all pregnancies. About 80% of all pregnancy losses occur in the first trimester. Patient experiences of seeking and receiving healthcare for early pregnancy loss can have long-term implications on their well-being. While individuals often present to emergency departments (ED) with early pregnancy loss symptoms, evidence suggests patient needs are not being met within this setting. There is a dearth of research on women's experiences utilizing the midwifery care as an option for early pregnancy loss.

Research Questions: This exploratory qualitative study examines two primary research questions: (1) What are the experiences of Ontario midwifery clients accessing and receiving healthcare in cases of early pregnancy loss (EPL); and (2) What are the experiences of midwives in providing early pregnancy loss care for their clients? The overall objective of this study is to understand how the healthcare-related experiences can be improved in cases of early pregnancy loss.

**Methods:** Semi-structured qualitative interviews were conducted with midwifery clients (n=14) and midwives (n=10). Two analytic approaches were taken for the analysis of participant interview data: healthcare journey mapping and thematic network techniques.

**Findings:** Both the healthcare trajectories and experiences of clients accessing and receiving midwifery care for early pregnancy loss varied considerably. Four main themes were identified as the aspects of midwifery care that made the biggest differences on clients' experiences of receiving care for early pregnancy loss: (1) Accessing care for early pregnancy loss, (2) Continuity and following-through, (3) Compassionate and supportive care, and (4) Knowledge, information and choice. Overall, the findings suggest clients benefit from compassionate,

individualized support during their early pregnancy loss. Midwives' experiences constraints related to their workload, clinic culture, local resources available, and compensation model that impacted their ability to respond to clients' needs and expectations.

Conclusion: Interventions to improve client care should look beyond client-provider interactions and consider ways to improve midwives' experiences and their ability to meet their client needs. Furthermore, to improve women's experiences, a more coordinated, patient-centered response at a systems level is needed. As this is the first study to examine the midwifery model of care for early pregnancy loss, findings from this study contribute to recommendations for practice, policy, and research.

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# **Dedication**

I would like to dedicate this thesis to my family.

To Ron, who understood when I had a "frying pan" moment that changed our plans, and who held me down to Earth.

To Linden, who knew I could do it all along, even if he teased that it would take 1000 years.

To Eli, who started school at the same time, and then could not remember it any other way.

This is yours to celebrate too.

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# **List of Abbreviations**

AOM Association of Ontario Midwives

CAM Canadian Association of Midwives

CMO College of Midwives of Ontario

D&C Dilation and Curettage

ED Emergency Department

EMCM Expanded Midwifery Care Model

EPAU Early Pregnancy Assessment Unit

EPL Early Pregnancy Loss

GP General Practitioner

HRTO Human Rights Tribunal of Ontario

MD Medical Doctor

PAIL Pregnancy and Infant Loss Network

RM Registered Midwife

Rx Pharmacy/Prescription

U/S Ultrasound

# **Chapter 1: Introduction and Literature Review**

## 1.1 Introduction

Early pregnancy loss is commonly defined as the loss of a pregnancy within the first 13 weeks of gestation.<sup>1</sup> While accurate rates of early pregnancy loss are difficult to determine,<sup>2,3</sup> approximately one in four pregnancies end in miscarriage, 80% of which occur in the first trimester (<13 weeks gestation).<sup>4-8</sup> Although the causes for miscarriage are largely unknown, early pregnancy loss is most attributed to chromosomal anomalies,<sup>9</sup> but is also associated with other factors, such as increased maternal age.<sup>3,10</sup>

Early pregnancy loss is usually identified either by ultrasound or by common symptoms, such as vaginal bleeding and painful uterine cramping. 4.5 The onset of symptoms often prompts women to seek and access healthcare services. 11-13 The emergency department (ED) is the most commonly accessed healthcare setting for miscarriage both provincially and nationally despite the availability of other care options, such as that from primary care providers. 12,14-17 Recent statistics reveal that in Ontario, 25,000-30,000 women seek care in the ED for miscarriage symptoms per year, representing 1% of all ED visits. 16,17 Given the relatively high rates of this early pregnancy complication, care for early pregnancy loss contributes to the strain on the already "overburdened" emergency care system. 15 More concerning is the large body of knowledge that has suggested women's healthcare needs for privacy, information and compassionate care when receiving care for early pregnancy loss are not being met within the ED care setting. 2,11,12,18,19 Thus, considering how to improve the experiences of patients seeking early pregnancy loss care is important for both improving health outcomes and strengthening the healthcare system, and is the goal of this research.

## 1.2 Literature Review

1.2.1 What are women's experiences seeking and receiving care for early pregnancy loss?

A recent scoping review of the research literature on pregnancy loss identified that women's experiences of seeking and receiving healthcare services for early pregnancy loss are largely negative. <sup>18</sup> In addition to women's physical needs or symptoms not being recognized or attended to, <sup>19</sup> studies largely suggested women's emotional needs are also not being met. <sup>18</sup> For example, studies showed women are often subjected to insensitive language, <sup>17,20</sup> and that communications with care providers lack in the needed emotional support, compassion, and acknowledgment of their loss. <sup>12,17,21-23</sup> Additionally, women are frequently not receiving pertinent information to help them to understand what is happening, what to expect, and how to make informed decisions about their care. <sup>11-13,18,23</sup> Furthermore, patients are not receiving adequate follow-up care with appropriate healthcare providers that attends to ongoing emotional and physical needs after a pregnancy loss. <sup>2,18,24-26</sup> Evidently, healthcare systems can be more responsive to women's needs in cases of early pregnancy loss, and centring women's experiences can potentially offer guidance on how to improve care quality.

Interestingly, there does not appear to be consensus within the literature on what constitutes patient experiences. For example, Wolf<sup>27</sup> described patient experiences within healthcare systems as "occurrences or events that happen...across the continuum of care". <sup>27(p.7)</sup> Frampton<sup>28</sup> suggested instead that patient experiences centre around "interactions" with care providers and the care received within environments. In a systematic review that explored the links between patient experiences and clinical safety and efficacy, Doyle et al<sup>29</sup> similarly uncovered varying understandings of what constitutes patient experience. Through their analysis they identified two broad aspects to patient experiences: the "relational" aspects, referring to the

"interpersonal aspects of care", and the "functional" aspects of healthcare experiences, referring to patients' expectations of healthcare safety, effectiveness and efficiency. <sup>29(p,2)</sup> Taking a different approach, Bate and Robert<sup>30</sup> suggested patient experiences are a "particular and very special kind of knowledge acquired from close and direct person observation or contact", <sup>30(p,309)</sup> thus seeing patient experiences as more than just occurrences or interactions. The authors go on to assert this knowledge is "expressed in what a person thinks, feels and says" about their experiences. <sup>30(p,309)</sup> McCarthy et al, <sup>31</sup> drawing on this earlier definition, suggested that more attention should be paid to the emotional aspects of patient experiences. Thus, due to the complexity and lack of consensus of how patient experiences are defined, for purposes of this study, this study has taken a broad and inclusive view of patient experiences.

Despite the lack of consensus within the research literature, there appears to be agreement that improving patient experiences is important. Internationally, increased attention has been paid to the importance of patient experiences as a component of healthcare quality,<sup>32</sup> and as a pillar of what is often referred to as the 'Triple Aim' of health systems, along with improving population health and reducing healthcare costs.<sup>33,34</sup>

## 1.2.2 What factors contribute to negative healthcare experiences for early pregnancy loss?

Taking a health systems approach to understanding why healthcare services, particularly in the ED, are not meeting the needs of patients is important. First, still centering the experiences of patients, understanding provider experiences can offer some insight. Studies that included the perspectives of providers delivering early pregnancy loss care highlighted how challenges within the healthcare setting, such as time constraints in a busy ED environment, prevent them from properly attending to the holistic care needs of patients.<sup>2,11,14,26,35</sup> Providers' skills, knowledge and confidence are also impacted by an apparent lack of preparation and lack of specialized

bereavement training for providing miscarriage care.<sup>2,14,35</sup> Providers' attitudes and beliefs on miscarriage also shape the care they provide.<sup>14</sup> For example, as providers work within a context in which miscarriage is seen as common or routine, they may not understand or acknowledge the sense of urgency,<sup>11-13</sup> or the emotional pain some women are experiencing.<sup>12,24,36-38</sup> Unfortunately, such patient-provider interactions can leave women feeling their concerns are being minimized,<sup>12,24,36-38</sup> and that they were "brushed off",<sup>19</sup> or disempowered and marginalized.<sup>12</sup> Radford and Hughes<sup>39</sup> suggested more research is needed on healthcare providers' experiences and their "ability to support and influence the woman's experience" during early pregnancy loss.<sup>39(p,1463)</sup>

The healthcare setting of service delivery, or the care environment, has also played a role in shaping women's experiences. <sup>2,11,18,19,40</sup> At the organizational level, EDs provide emergent care, thus the ED care environment is not necessarily designed to attend to privacy and emotional needs of those undergoing early pregnancy loss. <sup>19</sup> The research literature has described the emergency environment as being chaotic, <sup>11,19</sup> busy, <sup>41</sup> and public. <sup>2,13</sup> Women's experiences within the ED environment have also been accompanied by long wait times, <sup>11,12,19</sup> and a lack of privacy, <sup>2,13,20</sup> which have further contributed to their feelings that they are not a clinical priority. <sup>12,20,22,23</sup> Furthermore, the literature has suggested that women often feel out of place as they wait among ill patients, or among other women with healthy pregnancies within the maternity-ward setting. <sup>13,20,22,42</sup>

Why, if patients are not getting their needs met within the ED, does the ED remain the first-choice destination for receiving care for early pregnancy loss? The emergency department may be chosen for matters of convenience due to location and hours of availability, <sup>11-13</sup> or for its ability to provide a timely diagnosis and treatment. <sup>43</sup> Patient access to care providers may also

play a role, as they may not have an "established" relationship with a maternity care provider in early pregnancy, <sup>15</sup> or they may be impacted more broadly by provider availability. <sup>12</sup> Women's knowledge of miscarriage, or lack there-of, as well as the information they have access to prior to seeking care, may also impact their decision to attend the ED. <sup>11</sup> Several studies have suggested a broader culture of silence around miscarriage may contribute to women not knowing what to expect physically or emotionally. <sup>11,12,22,37</sup> Thus, even though miscarriage is rarely an emergency, <sup>5</sup> distressing symptoms and an elevated concern about the risk to the pregnancy are likely to prompt seeking urgent care. <sup>11,12</sup> Studies have additionally suggested the role of the internet should not be underestimated in aiding patient decision-making prior, during, and after a miscarriage <sup>11,44-46,47</sup> In Ontario, reputable online resources that offer advice on what to do in cases of miscarriage symptoms often direct individuals to seek medical care, and in some cases emergency care, both of which may prompt more ED visits. <sup>48-50</sup> Thus, there is a need to consider the roles of culture, media, and health care organization and accessibility in shaping women's navigation decisions when seeking healthcare.

1.2.3 What are the implications of negative patient experiences when receiving care for early pregnancy loss?

Negative patient experiences of healthcare for early pregnancy loss can lead to decreased patient satisfaction with their overall care<sup>2,19,23,26</sup> and can contribute to decreased trust in existing healthcare services.<sup>44</sup> More importantly, studies have suggested that patient experiences within a healthcare setting play an important role in shaping how individuals feel overall about their early pregnancy loss, having implications for women's well-being following miscarriage.<sup>21,25,51-53</sup> The psychological and emotional impacts of miscarriage have been well-documented in the research

literature. 52-56 For many women, the early loss of pregnancy and its accompanying symptoms can be distressing. 52-56 Although individuals' feelings about their pregnancy or responses to their miscarriage cannot be universalized, 42,57-59 many studies have reported that women may experience sadness, shame, and personal blame connected with pregnancy loss. 11,36,38 Miscarriage can also have implications for women's mental health over short and long-term periods. 51,53-56 For example, symptoms of grief, depression and anxiety can be experienced over a period of several years following miscarriage. 51,54 Moreover, some research has suggested that mental wellbeing after the miscarriage may contribute to increased levels of anxiety and reduced attachment in subsequent pregnancies. 31,60-62 Given the high rates of miscarriage, and the impact it has on women's mental health, this maternal health issue is of public health concern.

The meaning ascribed to miscarriage is an important consideration to understand why early pregnancy loss can be distressing for some women. <sup>37,38</sup> For many, miscarriage is understood to be a loss of a baby, or a death, for example. <sup>12,36</sup> Studies have highlighted that the meanings attached to pregnancy, motherhood and miscarriage can vary across cultures <sup>38,63</sup> as well as between co-existing cultural understandings. <sup>37</sup> Murphy and Merrell <sup>42</sup> suggested that our cultural understanding of the emotional experiences associated with early pregnancy loss can impact how we care for those experiencing early pregnancy loss. Thus, to understand the healthcare needs of women undergoing early pregnancy loss we need to have a better understanding of the meaning of the loss for each individual patient. <sup>42,64</sup> Understanding the meaning patients ascribe to early pregnancy loss can further offer insights into how women assess the urgency of the situation, <sup>11,37,46</sup> when and how they access and utilize health services, <sup>11,12,65</sup> what their healthcare expectations are, <sup>37</sup> and what help needs to be offered to improve available services. <sup>43</sup>

# 1.2.4 How do we improve women's experiences within healthcare settings?

Overwhelmingly, the literature surrounding women's experiences of early pregnancy loss across healthcare settings has emphasized the need for compassionate care that meets the complex healthcare needs of each patient. 17,18,37,42 How to improve women's experiences has been addressed in a few ways. For example, several studies have offered recommendations for improvements within the ED, focusing on interventions related to both the staff and the environment. Recommendations within the literature have included ensuring personnel receive training on how to provide sensitive and personalized care, <sup>25,42,52</sup> and improving the information and resources provided to patients. 19,25,66 Additionally, Edwards et al<sup>66</sup> recommended increasing the scope of practice of ED nurses to improve patient access to early pregnancy loss care, particularly in rural and remote communities. Recommendations for the ED care environment itself have emphasized patients' needs for privacy<sup>13,66</sup> and separation from either people who are ill or have a healthy pregnancy. 20,22,41,42 While these interventions likely have benefits for improving the healthcare experiences for women, I question whether they offer change to the fundamental and underlying function of the ED, the role of staff, or the design of that environment.

In Ontario, the ED is not the only healthcare option for women in cases of early pregnancy loss. Over the last decade, there has been an increasing amount of attention and interest in Early Pregnancy Assessment Units (EPAUs) as an alternate model of care. <sup>15,46,67</sup> A care model originating in the UK,<sup>67</sup> the EPAU is a specialized clinical setting, often attached to hospitals, that focuses on complications of early pregnancy, including first trimester losses. <sup>11,15,68</sup> Most EPAU clinics are staffed by registered nurses (RNs) and referrals to the unit are made by ED staff or other primary care providers, such as physicians and midwives. <sup>68-70</sup> In Ontario,

EPAUs are being promoted as cost-effective and patient-centred approaches to improve the quality of care for those undergoing miscarriage. <sup>15,17,70</sup> Currently, EPAUs are found in 29 provincial hospitals, representing less than half of the total hospitals. <sup>15</sup> While patient satisfaction is reportedly higher within EPAUs, <sup>67,69</sup> issues related to quality of care, such as wait times or the sensitivity of care providers, are reportedly similar to those noted in the context of receiving care within the ED. <sup>46</sup> In Ontario, further challenges related to the accessibility of EPAUs have been identified, both in terms of the limited hours of operation and their locations, as most EPAUs are located in urban settings. <sup>71</sup> Moreover, the EPAU model does not necessarily address concerns about the overburdening of emergency departments, as many EPAU patients are referred from EDs, meaning patients are still attending and seeking care in the busy ED environment first. <sup>11,15,71</sup> More research is needed on women's experiences utilizing this model of care. <sup>18</sup>

Primary care providers such as physicians, nurse practitioners, and registered midwives, also provide some of the miscarriage care provincially, but to a smaller extent than within hospital-related settings. <sup>14,17</sup> Less attention has been paid to how out-of-hospital, primary care providers could contribute to improving women's experiences of care for early pregnancy loss, but it is thought they too play a role. <sup>11</sup> The midwifery model of care, which is by design "women-centred", <sup>72,73</sup> may be a promising model of care for early pregnancy loss. The midwifery model centres care around clients by promoting informed choice and continuity of care, and offering clinical care within the home, clinic and hospital settings. <sup>74,75</sup> Regulated as a health profession in 1994, over 900 midwives currently provide primary healthcare for low-risk pregnant clients in over 300 communities, and attend 16% of births provincially. <sup>76,77</sup> While midwives provide some early pregnancy loss care to their clients, the potential for the midwifery model to address women's healthcare needs at both the individual and broader maternal

healthcare system levels, and to improve quality of care for early pregnancy loss, has remained largely unexplored.

The extent to which care providers, such as midwives, can provide or manage care for early pregnancy loss is strongly connected to their scope of practice. Following a diagnosis, often made by ultrasound, women are typically offered three clinical management options aimed at completing the miscarriage<sup>5,78,79</sup>: expectant management, also referred to as "watchful waiting" medical management, which uses medication to evacuate the uterus; and surgical management, which uses surgical means to complete the miscarriage. As the three options vary somewhat in efficacy but offer similar safety outcomes, findings within the research assert that the preferences of women should be considered, findings within the research assert that the preferences of women should be considered, findings within the research assert that decision-making regarding the management of their pregnancy loss. Findings within the research assert that the preferences of women should be considered, findings within the research assert that the preferences of women should be considered, findings within the research assert that the preferences of women should be considered, findings within the research assert that the preferences of women should be considered, findings within the research assert that the preferences of women should be considered, findings within the research assert that the preferences of women should be considered, findings within the research assert that the preferences of women should be considered, findings within the research assert that the preference of women should be considered, findings within the research assert that the preference of women should be considered, findings within the research assert that the preference of women should be considered, findings within the research assert that the preference of women should be actively involved in decision-making regarding the management of their pregnancy loss. Findings within the research assert that the preference of women should be actively involved in decision-making regarding

Changes to the midwifery scope of practice as well as payment and organizational models, may create opportunities for midwives to offer more options to their clients, options that women are saying they want.<sup>80</sup> For example, recent refinements to the midwifery scope of practice to include the addition of point of care ultrasonography may increase the potential for midwives to diagnose early pregnancy loss in out-of-hospital settings.<sup>83,84</sup> Additionally, while payment within caseload midwifery has been discussed as a potential challenge to providing early pregnancy and miscarriage care, <sup>14,86</sup> the recently introduced Expanded Midwifery Care Models (EMCMs) offer

alternative organization and payment models that may increase midwives ability to address community needs.<sup>87</sup> The midwifery pharmacopeia, which describes what medications midwives can administer or prescribe, is also currently under evaluation.<sup>88</sup> As less invasive management options for early pregnancy loss can be safely offered in out-of-hospital clinical settings,<sup>79,89</sup> and there is evidence to support these clinical management options being offered by trained, non-physician care providers,<sup>90</sup> a variety of options for the provision of early pregnancy loss care can be explored, including that of midwifery care.

Given the reach of midwifery services in Ontario, and the priorities of the current government to seek and promote cost-effective approaches to healthcare provision, 91,92 it is timely to consider whether midwives can play a role improving access and quality of care for early pregnancy loss in the province. Unfortunately, there is a considerable lack of research on both midwifery models of care and clients' experiences of that care for early pregnancy loss. 18 Existing international research that includes midwifery care 21,23 is also limited in its application for our healthcare system context, as midwifery models of care vary considerably across regions, even within the country. 77

# **Chapter 2: Study Aims**

This research study examined: (1) What are the experiences of Ontario midwifery clients accessing and receiving healthcare in cases of early pregnancy loss?; and (2) What are the experiences of midwives in providing early pregnancy loss care for their clients?

Focusing on the experiences of midwifery clients, I explored the following sub-questions:

- a. What are women's experiences of the care they receive from midwives in Ontario in cases of early pregnancy loss?
- b. What knowledge, beliefs and attitudes do midwifery clients have about their early pregnancy loss care options?
- c. How can healthcare experiences be improved from the midwifery clients' perspective?

The following sub-questions were explored for midwives:

- a. How do midwives approach the provision of care in cases of early pregnancy loss?
- b. Is there a midwifery model of care for early pregnancy loss?
- c. What challenges do midwives experience when providing early pregnancy loss care?

The goal of this study was to improve our understanding of how midwifery care is experienced in cases of early pregnancy loss within the Ontario healthcare context, and how the midwifery model of care can be improved to meet the needs of women. The overall goal was to inform practice and provide policy recommendations to improve the quality of care for women experiencing early pregnancy loss in the province.

# **Chapter 3: Methods**

# 1.1 Study Design

An exploratory qualitative study design was adopted to address the research questions outlined above. As there is a paucity of research about midwifery care for early pregnancy loss in Ontario, it was felt an exploratory study would help gain "initial insights" into issues faced by midwives and clients, and highlight areas for future investigation.<sup>23,93</sup> Additionally, a qualitative study design was chosen as the best means to capture and understand the experiences of those most impacted within a healthcare system, the users and providers.<sup>94</sup>

# 1.2 Research and Theoretical Approaches

To centre this women's health research topic within a healthcare system context, I adopted a feminist research approach. While there is not a defined set of criteria for what constitutes feminist research, Westmarland<sup>95</sup> suggested that research utilizing this approach emphasizes the value of centering women's voices and experiences, the importance of addressing power imbalances, and the requirement for social change as a goal. To centre women's experiences of receiving care for early pregnancy loss and the experiences of midwives, which is a largely female-dominated profession, I adopted a feminist research approach which informed every aspect of my study design and methods.

While not a theory-driven study, I naturally leaned toward the application of two theoretical lenses, that of critical feminism and systems theory.

#### 1.2.1 Critical Feminist Lens:

Critical feminism posits that there are no universal experiences, but, more specifically, to imagine all women's experiences are the same, or that there is only one gendered experience, is

overly simplistic.<sup>96</sup> Instead, these experiences are shaped by complex cultural "elements", such as race, ethnicity, gender, class, and sexuality, elements which are made and reproduced "within asymmetrical relations of power".<sup>96(p.297)</sup> Thus, "culture is not neutral" within this perspective.<sup>96(p.298)</sup> Applying a critical feminist theoretical lens within this study gave room to consider a diversity of experiences while situating findings within a cultural context.

Additionally, applying a critical feminist theoretical lens offered insight regarding how cultural meanings and various types of knowing can move us away from seeing qualitative findings as universal truths.<sup>97</sup> Integrating this lens into the analysis contributed to understanding power inequities within a broader healthcare and societal context. (98)

# 1.2.2 Systems Theoretical Lens

Meadows<sup>99</sup> defines a system as a "set of things…interconnected in such a way that they produce their own behaviour over time". <sup>99(p,2)</sup> Originally derived from the study of ecological and economic systems, systems theory offers a way to understand the complexities of how systems act or behave under certain conditions. <sup>100</sup> Systems are understood to be dynamic, unpredictable, resistant to change, self-maintaining, and shaped by the interactions and connections between its parts. <sup>40,51,99</sup> Thus, the overall behaviour of a system does not always reflect the "stated goals" or the purposes of its parts. <sup>99</sup> Applying a systems theoretical lens within health research offers a way to situate findings within a broader healthcare context, by considering the complex interactions and processes that exist between its players, such as patients and providers, and its components, such as regulation and funding. <sup>100-102</sup> Additionally, applying a systems lens to healthcare problems, such as how to improve quality of care, can be helpful when identifying and developing interventions or in anticipating their implications. <sup>100,101</sup> Thus, utilizing a systems theoretical lens for this study helped situate client and midwife experiences within a broader

maternal healthcare context rather than seeing them as isolated phenomenon, to identify connections between findings, and to identify creative interventions to improve quality of care.

## 1.2.3 Applying two lenses

To date, there has been little overlap in qualitative research between the two theoretical approaches above. Both approaches, however, find common ground in recognizing the important role culture plays in shaping the values, attitudes, and beliefs of individuals and social institutions. <sup>65,95,96,103</sup> Additionally, both theoretical lenses offer insights on how to effect change, <sup>95,99</sup> either at the cultural and institutional level, <sup>103</sup> or within systems, done so by shifting either the purpose of its parts or how they interconnect. <sup>99</sup> Stephens <sup>104</sup> suggested an overlap between research approaches might occur when systems research takes a gender-sensitive approach. By placing importance on finding and elevating less-dominant voices, greater systems understanding is accomplished. <sup>104</sup> As this was an exploratory study, both theoretical lenses were inductively explored for their applicability.

## 1.3 Study Sample, Eligibility and Recruitment

## 1.3.1 Study Sample

This study took place in Ontario, Canada. Participants were eligible to participate if they were over the age of 18, and met the additional criteria outlined below. No participants were excluded from participating based on gender, race, ethnicity or religious affiliation, ability, or socio-economic status. To best meet the study objectives, I aimed to involve approximately 20-25 participants representing two groups, midwifery clients and midwives.

#### 1.3.2 Inclusion Criteria

For purposes of this study, midwifery clients were defined more broadly to include individuals who contemplated, requested, or utilized midwifery care for their early pregnancy. This broader definition was taken to provide greater insight into how midwifery services are accessed and utilized in early pregnancy, and in cases of early pregnancy loss. To be eligible for this study, client participants would have had to personally experience an early pregnancy loss within the first 13 weeks of pregnancy. For participants who experienced a missed miscarriage, the gestational age of the loss was determined by the gestational age at the time of diagnosis, not treatment. The duration of time from the early pregnancy loss to the interview was greater than one month but less than three years, taking into consideration recovery time following a loss, client recall, recruitment needs, and the desire to remain current within a changing healthcare context. Midwives were eligible to participate if they were practicing in Ontario and had greater than one year of professional experience in the province.

#### 1.3.3 Recruitment

Recruitment letters (Appendix A) and posters (Appendices B&C) for both participant groups were sent to professional contacts and to midwifery clinics, reaching over 50 midwifery practices across the province. Midwives and practice administrators were encouraged to post materials in their clinics or on their practice group's social media sites. Recruitment materials (Appendix D) were additionally posted in the Association of Ontario Midwives (AOM) online newsletter, sent to all Ontario midwives weekly over a period of three weeks. In addition to the above means of recruitment, client participants also reported seeing the study posted on parenting group social media sites, suggesting materials were also spread by word of mouth. By taking a staggered approach to recruitment over the period of a few weeks and evaluating the

progression of participant uptake, the recruitment strategy was itself an iterative process. As participant interest was brisk following the outlined activities above, no other recruitment strategies were deployed.

Individuals interested in participating in the study made initial contact primarily by email. All inquiries were answered, and all interested participants were provided with a Letter of Information and Consent Form (Appendices E&F), which outlined the nature of the study and its procedures, as well as the voluntary nature of participation. Eligibility criteria was confirmed over email correspondence.

#### 1.4 Data Collection

Interviews were arranged at a time and place that was convenient for participants. While most interviews took place by phone due to the geographic distribution of participants across the province, three client participants preferred meeting in-person. At the time of the interview meeting, the Letter of Information was reviewed, and a signed or recorded verbal consent was obtained.

# 1.4.1 Demographic Information and Participant Preferences:

After obtaining consent, and prior to commencing the recorded interviews, participants were assigned an identification number. Following the advice of Westmarland<sup>95</sup> on considerations while conducting feminist research, participants were given the opportunity to choose their own pseudonym, which was well-received. Client participants were asked to voluntarily provide demographic information, including age range, race/ethnicity, education level, gender identity, relationship status, and geographic setting (i.e. rural, urban), which was recorded on an ethics approved form (Appendix G). The purpose of collecting demographic information for client participants was to gain insight on how individual's experiences may vary by social or

geographical context. To be sensitive to the experiences, values, and feelings of participants, and to avoid the use of insensitive or triggering language, I encouraged and adopted the language-use preferences of participants, by, for example using the word 'miscarriage' versus 'loss' or "abortion", or 'baby' versus 'fetus'. <sup>105,106</sup> All demographic information was de-identified and stored securely. Information collected from the midwife participants prior to the interview was limited to duration of midwifery work experience, as related to their eligibility criteria. Further information related to their practice setting was elicited as part of the interviews.

## 1.4.2 Semi-Structured Interviews

All participants took part in semi-structured interviews. This interview approach was chosen to allow for flexibility within the interview and to centre and adapt to the experiences and stories shared by participants. Additionally, employing a feminist research approach, attempts were made to keep interviews more conversational, and to give opportunity for participants to describe their experiences and centre what they felt was important. 95,107 An ethics-approved interview guide (Appendices H&I) was developed for each participant group with study objectives and research questions in mind. Within the interviews, client participants were asked to talk about their experiences of utilizing healthcare services for their miscarriage, the role of midwives in their care, and suggestions they may have on how their experience could be improved. Additionally, points of clarification related to clients' healthcare journeys, of accessing or utilizing healthcare services, were made throughout the interviews. Interviews with midwives centred around their experiences providing early pregnancy loss care to their clients, with questions related to the midwifery model of care, how the model fits within the broader maternity care system, and whether there are any challenges to providing early pregnancy loss care.

Interviews were largely conducted over a period of 3 months, starting late November 2019. Interviews varied in length from 13 minutes to over an hour, but most interviews were between 30-50 minutes. Of note, I found that the length of the interviews was to some extent led by the participants and how much they delved into the topic or talked about their experiences. All interviews were recorded on a hand-held recorder and then transcribed verbatim. All participants were offered a copy of their own interview transcript and a summary of results.

In addition to the interview recordings, notes were taken during and immediately following the interviews, which captured key topics arising during conversations. Taking an iterative and reflective approach, notes were additionally used to develop themes and topics to explore in subsequent interviews. Transcripts and notes were shared with my supervisor as a means of verification of early findings.

#### 1.5 Ethics

This study received ethics clearance from the University of Waterloo Office of Research Ethics (UW-ORE#41475) for all procedures related to recruiting participants and for collecting and storing research data. Given the sensitive nature of the research topic, and also the role of the researcher as a clinician, additional consideration was given to the methods and procedures within the study.

First, because experiencing an early pregnancy loss can be emotionally difficult, it was anticipated that speaking about their experiences might be challenging for some participants.

To mitigate possible risks to the participants' emotional wellbeing, all participants were informed of the topic, what to expect prior to participation in interviews and were reminded that their participation in the study was voluntary. Despite not being needed, contingency plans were made to discontinue an interview or direct a participant appropriately if they were in apparent

distress or there were heightened concerns about the risk of harm arising from participation.

Along with a participant feedback letter (Appendix J), participants were offered information regarding community resources following the interview (Appendix K). In reflection, while some participants experienced a wide range of emotions during the interviews, almost all expressed appreciation for the ability to discuss their experiences.

Another concern addressed in the ethics application was related to my positionality as a as a clinician-researcher. To reduce the risk of creating confusion regarding my role and to reduce issues related to power-imbalances between researcher and client participants, I took several actions during recruitment and data collection. For example, all recruitment materials as well as the Letter of Information and Consent Form included my name and credentials. I made effort to state that I was a registered midwife at the time of the interviews and clarified my primary role within the study as investigator. Additionally, while I developed plans to avoid providing clinical advice or opinions, and to remove participants' personal healthcare questions, these issues did not arise.

Lastly, as the midwifery community in Ontario is relatively small, precautions were taken to ensure the confidentiality of all participants by de-identifying transcripts and by not using identifiers when presenting the findings.

# 1.6 Participants

In total, 23 participants took part in this study. One participant met the criteria of both participant groups, and their data was incorporated and analyzed as such.

## 1.6.1 Midwifery Clients

Fourteen clients participated in this study. For detailed client demographic information, see Table 1 at the end of the chapter. As previously noted, this study took a broad definition of

midwifery client. As such, despite their intentions to have midwifery care for their pregnancy, five clients were not in midwifery care at the time of their early pregnancy loss because their pregnancy loss occurred either before they were able to sign-up for care, or before their intake appointment with midwives. Nine clients had started their midwifery care at the time of their loss(es).

Midwifery clients were situated in several regions across Ontario. At the time of writing, Ontario was divided into five interim health regions<sup>109</sup> The regional distribution of client participants occurred as follows: North (4), East (2), Central (2), West (6). Interestingly, no clients resided in Toronto, the fifth health region and provincial capital. Participants resided in both rural communities (n=3) and urban centres (n=11).

Participant ages in this group ranged from 25 to 39 years of age, with most participants being in their 30s. All participants identified as female and were in heterosexual partnerships, and 11 were married. This participant group was highly educated. All participants had some post-secondary education, and four had obtained a master's degree. While three participants identified as biracial or people of colour, most participants identified as white.

Clinically, this was an interesting participant group. While most participants had experienced one loss, five clients reported more than one early pregnancy loss, three of which had four or more early pregnancy losses. The timing of the pregnancy loss ranged among participants from 4.5 weeks to 13 weeks gestation. The duration of time that had passed between the most recent loss and the interview ranged from 6 weeks to 28 months. Interestingly, participants were quite equally divided between having a spontaneous or incomplete miscarriage (n = 7), or a missed miscarriage (n = 7). Eleven client participants disclosed that they were

either pregnant at the time of the interview or had given birth to a live infant since their early miscarriage.

#### 1.6.2 *Midwives*

Ten midwife participants who took part in my study practiced within a midwifery practice group model and received compensation for the care provided to clients by billable courses of care (>12 weeks of care or attending the birth). All midwives were practicing in various communities across Southern Ontario, although one midwife divided her time between providing care in a large urban centre and a remote community in Northern Ontario. The distribution of midwives across Ontario's five interim health regions is as follows: North (1), East (1), Central (3), West (5), Toronto (1). Most midwives provided care within a mixed rural/urban context.

Midwife participants varied in their clinical practice experience, ranging from 1.5 years to 20 years of midwifery practice. There were notably fewer midwives practicing within the 5 to 10-year period, with most either being early in their career or having over 10 years of experience.

## 1.7 Data Analysis

While I came to this research with some notions of what I expected to find, based on my own lived experience as a midwife, and by conducting a literature review, I endeavored to take an inductive approach to my research in which the experiences of participants lead the analysis. This approach aligns with feminist research methods which centre the analysis around participant experiences and their role in contributing to knowledge-building. Based on my findings, I utilized two analytic approaches: a thematic analysis to synthesize the rich qualitative data from interviews, and healthcare journey mapping, to further understand how

women navigate and move through the healthcare system when experiencing early pregnancy loss.

## 1.7.1 Healthcare Journey Mapping

Healthcare journey mapping, also called healthcare utilization mapping, describes a range of visual tools that centre patient experiences by outlining their trajectory of care across space and time through healthcare systems. Mapping healthcare journeys can provide insights on patient utilization patterns, but also the challenges facing health system users and potential points of intervention. In a similar study exploring women's experiences receiving care for early pregnancy loss, McLean and Flynn accompanied interview data with diagnostic journeys mapping, which provided additional insights on their participants' experiences.

While there was an intention to consider the use of this analytic tool within the study design and planning period, the decision to utilize healthcare journey mapping was more iterative, as its use as a tool was dependent on the findings that emerged from the data. As client participants often provided a narrative account of the steps they took when accessing and utilizing healthcare services, the data lent itself to this type of analysis. Direction on how to map the healthcare journeys was taken from an approach described and utilized by Kelly et al. Relying solely on data derived from interview transcripts, I mapped each clients' trajectory across healthcare settings, from the start of symptoms to their aftercare. Particular attention was given capturing the providers and services encountered and to decisions or symptoms that may have impacted participants healthcare journey. An early analysis of several healthcare journeys revealed key care "milestones" that participants moved through which further informed how to map and compare healthcare journeys. Once completed for each participant, the healthcare journeys were compared for points of commonality and difference. Taking a broader systems

perspective, I further attempted to analyze the healthcare journeys as a group, to identify what the data says as a whole about the healthcare context for early pregnancy loss in Ontario.

#### 1.7.2 Thematic Analysis

A thematic analysis was undertaken to summarize the breadth of rich data generated within this exploratory study. <sup>23,113</sup> It was felt that 'thematic network techniques', an analytic method put forward by Attride-Stirling, <sup>114</sup> complemented both critical feminist and systems theoretical lenses, and thus was utilized to analyze the interview data. This analytic technique emphasizes relationships and interconnections between findings and can help identify deeper meanings within the data. <sup>114</sup> Guided by the recommendations of Attride-Stirling, <sup>114</sup> the midwife and client data were analyzed separately following the steps described below. Data collection, transcribing and early thematic analysis took place somewhat concurrently, as this was an iterative process.

Step 1 – Coding the material: Following the transcribing of five interviews for each participant group, interviews were re-read to become familiarized with the data. Coding frameworks for both groups were developed using the recommendations from Attride-Stirling<sup>114</sup> to identify small sections of text or words, and salient or recurring topics which could be applied to the coding of the interviews. A description of each code was provided, and the frameworks were reviewed by my supervisor prior to undertaking the coding process. Applying the coding framework to "manageable" segments of text,<sup>114</sup> each transcript was coded in NVivo 12 Pro. The process of coding was iterative and as such new nodes were added or collapsed as themes or groupings of data emerged.

Step 2 - Identifying Themes: Following the coding of all interview transcripts, I reviewed and collapsed similar codes that had captured the same data. Major themes emerging from the codes were identified, described, and refined by working closely with the datasets. These themes were then grouped together to connect related data. At this stage, I developed a preliminary thematic network and described each of the basic and organizing themes for further development.

Step 3 – Constructing the Networks: Themes were further grouped and arranged, forming the basis of a network of themes, in which a "basic", "organizing" and "global" themes were identified and connected as possible. The relationships between themes were visually explored through the drawing of "non-hierarchical web-like representations", in which concepts were connected. This step was repeated and revised a few times until the networks best described the relationships between the emerging themes.

Step 4 – Describe and Explore Thematic Network: The contents of the emerging thematic networks were then described, drawing on original text (i.e. quotes) to support network descriptions around each global theme. This step resulted in a complex and large amount of data to be summarized but helped focus the analysis by highlighting more salient themes and patterns within the data.

Step 5- Summarize the Thematic Networks: Noting the key themes emerging in both datasets, it was decided to further explore the themes that had the largest impact on the experiences of the clients and the midwives. These key themes were further explained and summarized.

Step 6- Interpret the Patterns: Following the thematic analytic approach taken above, the main themes were interpreted by relating the findings back to the original research questions, and by

situating the findings in current policy and literature. At this point, both data sets were analyzed for relationships between them.

# 1.8 Positionality

I acknowledge I carry with me a set of world-views and experiences that inform and shape my understanding of the need for this research, how I have gone about it, and the findings that are derived from my analysis. As a white, middle-class, educated woman, I am also aware that I have considerable privilege. It is not lost on me that within the current social context, where the importance of social movements such as Black Lives Matter are highlighted, my voice is less needed. I additionally acknowledge that how I ascribe meaning to early pregnancy loss is influenced by multiple discourses, first as someone who has had two early pregnancy losses and grieved, and also as a midwife who frequently provides this care, normalizing this experience. Personal bias and experience aside, my newness as a qualitative researcher may present analytic limitations, but also a level of freshness within the conceptualization of this study and its findings.

**Table 1: Client Participant Demographics** 

Pseudonym	Age	Geographic setting	Racial/ Ethnic Identity	Relationship Status	Education	Type of Loss(es)/ Management	Timing of Loss (weeks)	Duration since (months)
Adelaide	25	Urban	West Indian/mixed	Common- Law	University	Missed/ Medical	12	28
Celeste	38	Urban	white/Italian	Common- Law	Master's	Incomplete/ Medical	<10	12
Claire	29	Urban	white	Married	University	Spontaneous	4.5-10	1.5
Emelia	35	Urban	white	Married	University	Missed/ Medical	10	~18
Emma	32	Urban	white	Married	Master's	Spontaneous	8	4
Leah	34	Small town/rural	white	Married	University	Missed/ Medical	10	19
Lynne	34	Urban	South Asian/mixed	Married	University	Spontaneous	8	13
Mariana	27	Urban	South American	Married	University	Missed and Spontaneous	6, 13	8
Marigold	32	Urban	white	Married	Master's	Missed/ Surgical	10	14
Mary	31	Urban	Undisclosed	Common- Law	Master's	Incomplete/ Medical	11	8
Sarah	39	Rural	white	Married	University	Spontaneous	7	~24
Scarlett	30	Urban	white	Married	University	Missed/ Medical	12	26
Shawna	33	Semi- Urban	white	Married	University	Missed/ Expectant	13	8
Teresa	39	Urban	white	Married	University	Spontaneous	<10	6

# Chapter 4 Mapping healthcare journeys of early pregnancy loss

# 4.1 Case studies and healthcare journey mapping

Within the interviews, participants described their experiences of navigating and utilizing services for early pregnancy loss, detailing the steps they took to in the process. Thus, their stories highlighted their trajectories of care as they navigated and moved through the healthcare system, and, when followed, these pathways represented their healthcare journey.

To analyze the data related to how clients access and move through the healthcare system, I mapped the healthcare journey of each participant. Through this process I identified four main stages of care, also referred to as "milestones" that most clients moved through on their journeys: accessing care, receiving assessment and diagnosis, management and treatment, and aftercare. In this chapter, I present four midwifery client case studies and their accompanying healthcare journey maps (Figures 1-4). In each healthcare journey map, I captured points of interaction with providers and identified services used (blue). I additionally noted any key decisions or symptoms that may have impacted clients' trajectories of care. Arrows depict directionality within the healthcare journey.

#### 4.1.1 Adelaide

Adelaide is a 25-year-old woman, who resides in an urban setting in Northern Ontario. During her interview, she described being diagnosed and treated for a missed miscarriage in her second pregnancy. As Adelaide had midwives with her first pregnancy, when she found out she was pregnant again, one-and-a-half years later, she decided to return to the same midwifery clinic. At her first appointment, Adelaide was given a requisition for a dating ultrasound to confirm her due date as her menstrual cycle had not returned between pregnancies and she was

still breastfeeding. Adelaide, feeling quite confident in her second pregnancy, decided to attend her ultrasound appointment at the hospital on her own. She thought she was approximately 12 weeks pregnant.

Adelaide recalled her ultrasound encounter in great detail. As she described her experience, she remembered thinking that the ultrasound technologist had an "anxious vibe to her" and was acting "super-weird" during her exam. She also recalled that the technologist proceeded from an abdominal to a transvaginal ultrasound without explanation and would not respond to questions about the exam's findings. Following the ultrasound, the technologist instructed Adelaide to call her midwife and wished her a "good weekend".

Adelaide immediately called her husband to share her concern about what the report would say. She then paged the midwife for more information. When the midwife called back she inquired whether Adelaide was home before relaying news, which she was. Adelaide was then informed by her midwife that there was no heartbeat on the ultrasound report, but that they would need to wait for the radiologist report to confirm the findings. Adelaide recalled that while she was aware miscarriages can happen, she felt "unprepared" for this possibility.

The next day Adelaide received a call back from her midwife with the full report which confirmed that Adelaide's pregnancy had stopped progressing at six weeks gestation. Adelaide was provided information about missed miscarriage and possible management options by her midwife. She also had time to ask questions. On the advice of her midwife, Adelaide was referred to an obstetrician in the community for medical management.

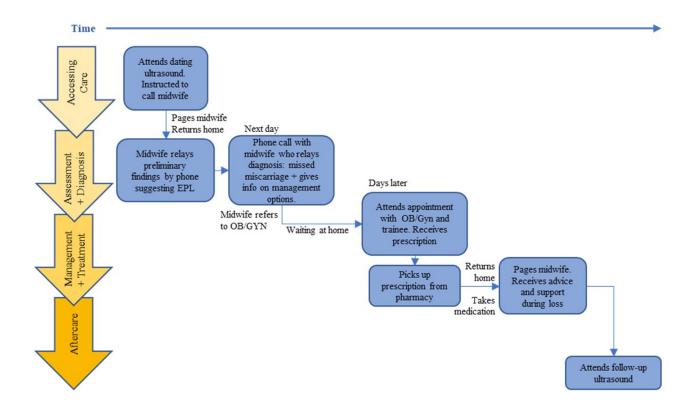
Waiting for the appointment with the obstetrician over a period of a few days was hard for Adelaide. She reported that from the time of diagnosis to her obstetric appointment she found herself wondering 'Am I gonna start to bleed? What's going on?', leading her to search for

information online. Additionally, she reported feeling "really weird being in the period where [there's a] baby that's no longer a baby inside" of her, and just "wanted it to be over with." During her wait, imagining her care would be timelier, Adelaide contemplated seeking care in the emergency department. Later she reflected that it would have been nice and simpler if her midwife could have prescribed the medication instead.

Once at her appointment with an obstetrician, Adelaide also received care from a trainee. Adelaide felt triggered and upset by the language used by the trainee, who repeatedly called her loss an "abortion". Making the decision to proceed with medical management, Adelaide left the appointment with a prescription for misoprostol. Adelaide recalled not knowing what to expect, which made her nervous. She called her midwife again for support and advice. She remembered thinking that she "might as well just page" to ask her midwife a few questions, as it would likely make her "feel better".

Adelaide completed the miscarriage at home without complications. Following her loss, she had an ultrasound but no follow-up appointments with care providers. In reflection, Adelaide expressed she was not always certain whose care she was in or when her midwifery care ended, but, ultimately, she felt comfortable paging her midwives when she needed to.

Figure 1: Adelaide's Healthcare Journey Map



#### 4.1.2 Shawna

Shawna is a 33-year-old woman who resides in a small city surrounded by a rural landscape in Southwestern Ontario. Shawna previously had two home births under the care of midwives. In her third pregnancy, Shawna experienced different pregnancy symptoms and had a nagging "feeling that something wasn't right". Her concerns prompted her to request being seen by a midwife at 12 weeks gestation. Although her midwife had difficulty finding a fetal heartbeat, she reassured Shawna that it was still early in pregnancy. The midwife also gave her a requisition for bloodwork to assess pregnancy hormone levels, which were reportedly normal.

A few days later, now on the weekend, Shawna started to experience sharp lowerabdominal pain. Shawna paged a midwife from her team. The midwife felt she could not rule out the possibility of early pregnancy loss and gave Shawna the option to wait until Monday for an ultrasound organized by the midwives, or to be assessed more urgently at the local emergency department.

Shawna, wanting to know what was happening, and not wanting "to sit there and think about it anymore", made her way into the emergency department on her own. Her blood results came back quickly and were again reported as normal, but while Shawna was waiting for her ultrasound, she started to experience some spotting. After several hours of feeling like she was on an emotional "roller coaster", Shawna had an ultrasound. Having had prior prenatal ultrasounds, Shawna noted the assessment was shorter than what she was used to. Following the ultrasound, Shawna was taken back to her ED assessment room to wait to see a physician.

Shawna recalled that when the doctor came in, she was already crying. "I already knew", she said. After discussing management options for early pregnancy loss, Shawna decided to return home and "do it naturally". She was in the emergency department for a total of 11 hours.

Shawna described what occurred over the next day:

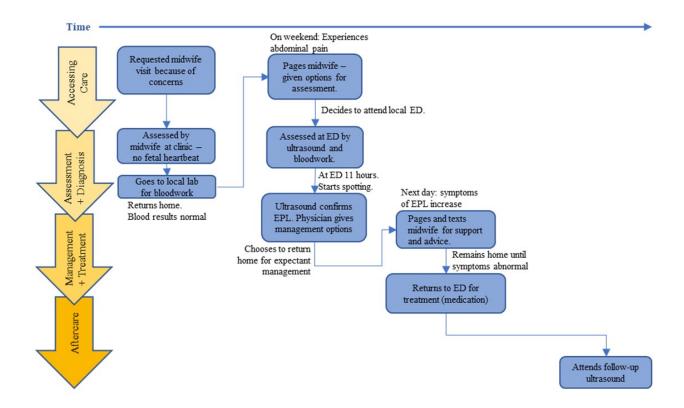
I started getting contractions, and there was more bleeding. Things started to happen, and I started to pass some big clots. And the midwives were very helpful. I was taking pictures and sending them to [the midwife]. I was comfortable at home going through it all.

Unfortunately, Shawna's symptoms started to deviate from the normal range described by her midwife, and she started to hemorrhage and expel large clots. Shawna and her husband returned to the emergency department where she was attended urgently and treated with medication. Shawna reported that losing large amounts of blood was the scariest part of her loss experience, saying, "I just felt completely out of control, and a little bit frightened at that point". After she completed her pregnancy loss, her doctor offered to take what are referred to as the

'products of conception' for testing. When Shawna requested bringing the remains home, a nurse kindly "packaged [them] up as beautifully as they could", to be later planted under a tree.

After her loss, Shawna had a follow-up ultrasound to ensure her miscarriage was complete but did not have any formal follow-up visits with a care provider. Shawna reported that despite the lack of follow-up appointments, she felt she could have reached out to her midwives at any point if she needed to.

Figure 2: Shawna's Healthcare Journey Map



## 4.1.3 Marigold

Marigold, a 32-year-old woman who lives in an urban setting, experienced an early pregnancy loss in her first pregnancy. Prior to her loss, Marigold started her prenatal care with midwives. At her first appointment she met a midwife on her assigned team, but left unimpressed with the encounter, feeling "brushed off" and that her questions were not being answered.

Just prior to 11 weeks gestation, around the time when she planned to share the news of her pregnancy with others, Marigold noticed some spotting while she was at work. Panicking, she called her husband who told her to call her midwives. Her midwives encouraged her to go to the emergency department if she thought something was wrong, suggesting she could receive an assessment and diagnosis faster than what midwives could order in the community. With this advice, Marigold rushed to the emergency department at her local hospital.

After being reassured by an emergency physician that her bloodwork was normal, the physician was unable to detect a fetal heartbeat by a portable ultrasound. Marigold proceeded to the ultrasound department, where she was assessed by a technician trainee, followed by a supervisor. It was then, as the supervisor completed the second scan, that Marigold knew something was wrong.

Marigold returned to a curtained-off exam room, and after some time was told by a physician that they were unable to find a heartbeat, and that she was experiencing a missed miscarriage. This was particularly hard news as Marigold had a reassuring ultrasound in the weeks prior. She recalled feeling like she "didn't know what to do because no one had ever talked to [her] about how prevalent miscarriages are [or]... about what to do if it happens". The physician then sent her home, telling her to wait it out.

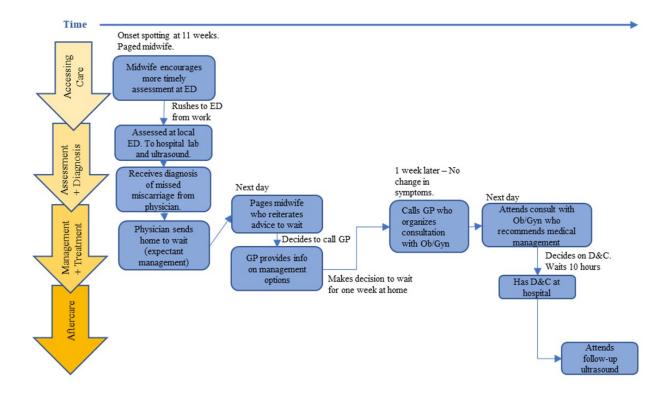
Not really understanding what to expect, or what would happen next, Marigold called her midwife the next day. Her midwife reiterated what she had been told by the emergency physician, that there was little to be done, and that she would have to wait out the pregnancy loss at home. Marigold, not feeling like she had enough information to know what to do or expect, called her family physician. After her physician described her care options, Marigold decided to wait a week at home prior to seeking further interventions. Marigold described that week as follows:

It was like the longest week ever, and I just felt awful because, y'know, you are not pregnant anymore. You are but you're not. You're in this weird limbo. I didn't feel like I had any support. I wasn't told where I could call if I needed someone to talk to, or where I could go. I wasn't offered an appointment with my midwife to talk about it. I wasn't offered websites [or] any resources. And it was a really long week of kind of trying not to Google things, but also just Googling things 'cause I had no other choice.

After the difficult week of waiting, Marigold called her GP again, who arranged an obstetric consult for the following day. When Marigold met with the on-call obstetrician she was offered medical management, but feeling unable to cope any longer, she elected for surgical management by dilation and curettage (D&C). "I couldn't do it anymore", she stated. After waiting another 10 hours for the obstetrician to be available, Marigold, to her relief, had a D&C.

Marigold had no follow-up or contact with her midwives after her earlier conversation. While she had a follow-up ultrasound arranged by the obstetrician, she reported having to find counseling and resources to support her recovery on her own.

Figure 3: Marigold's Healthcare Journey Map



#### 4.1.4 Mariana

Mariana is a 27-year-old woman who immigrated to Canada and lives in an urban community. In Mariana's first pregnancy, she experienced a missed miscarriage that was diagnosed by her physician in Ontario but was managed by an abortion clinic and hospital in South America. When Mariana found herself pregnant a second time, again in Ontario, she decided to try midwifery care because she perceived the midwifery model of care to be more "personal" and felt that it promoted greater client autonomy in decision-making.

Mariana was seen by her midwives for an intake appointment at 8 weeks, and then again at 12 weeks of pregnancy. At her 12-week appointment, Mariana reported that "everything seemed fine", but the midwife was unable to find a fetal heartbeat. The midwife explained that this can be normal at earlier gestations, and Mariana went home.

The next morning, Mariana started to experience some light spotting. She paged her midwife, an action that was the "first thing in [her] mind." Mariana was informed by the midwife that spotting in pregnancy can be normal and was told to page back if the bleeding increased.

The following morning, Mariana's bleeding had increased, and she paged her midwife again. This time the midwife informed Mariana she was likely experiencing another pregnancy loss. Mariana's midwife described her care options, including the option to stay home, and gave her direction on what to expect in terms of normal pain or bleeding, and what to do if her symptoms became abnormal. During that day Mariana continued to experience bleeding and cramping. She reflected on her decision and experience of remaining home as follows:

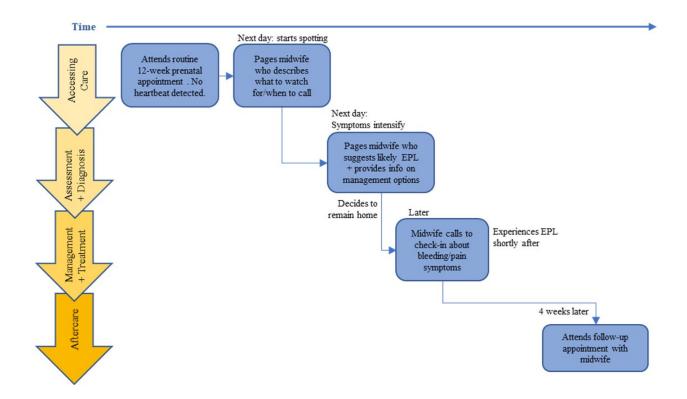
Well, it was really emotionally difficult, but I think it was a lot better than going to the hospital. The first time around, because it was my first pregnancy and I didn't know what to expect and everything, it was very stressful. And I, in general, find hospitals stressful,...having so many people around, and so many noises...So, I was kind of happy to be at home, [where] I had time to process that experience...at my own pace. ...I went for a walk, and I came home again, and was kind of able to manage my own experience that way. So, yeah, I think it was a better option for me.

That evening, Mariana's midwife called to check-in about the pain and blood loss. It was not long after that Mariana completed her miscarriage. She described knowing what had happened, because she "wanted to see if [she] could see [her] baby, and...was able to". As her midwives had advised her what to watch for over the next few days, and the bleeding and pain subsided, Mariana felt reassured that what she was experiencing was normal.

Four weeks later, Mariana had a final visit with the midwives where she had opportunity to ask some questions. In reflection, Mariana appreciated having this visit but felt it was too

short, and that she did not receive needed information regarding family planning and future maternity care options.

Figure 4: Mariana's Healthcare Journey Map



## 4.2 Comparing healthcare journeys for early pregnancy loss

The four case studies and accompanying healthcare journeys outlined above reflect some typical pathways taken by the midwifery client participants when receiving care for early pregnancy loss. To provide further context to the experiences presented above, I offer some further analysis of the similarities and divergences between participants' healthcare journeys at each care milestone.

### 4.2.1 Accessing care

By mapping the healthcare journeys of midwifery clients, I found that most participants (n=12) accessed healthcare for early pregnancy loss either when noticing

symptoms or with the diagnosis of a missed miscarriage by routine ultrasound. Three women described not seeking any healthcare for their symptoms, citing an early gestational age or minor symptoms not warranting clinical attention. Both a sense of urgency and a desire for more information regarding what was happening were often motivation for seeking healthcare services.

Participants accessed care in a variety of ways. Clients already in midwifery care frequently called their midwife as their first healthcare contact. Participants not in midwifery care accessed advice by calling either the midwifery clinic where they planned to get care, or care from their family physician, a walk-in clinic, or by attending the emergency department (ED). Seeking information online and calling Telehealth were also frequently used to help make decisions about who to call or where to go when symptoms arose.

### 4.2.2 Assessment and diagnosis

Most participants who experienced symptoms, such as bleeding or abdominal pain, received some form of clinical assessment. Where an assessment took place was somewhat related to the urgency of symptoms, but also timing. For example, unable to access community-based laboratory testing on the weekend meant some participants attended the ED. Within the interviews, the ED featured centrally as a location of care, whether clients chose to seek care in the ED for more timely assessment or in case of emergency, or whether they chose to avoid it, seeing the ED as a less than ideal location to receive care. The setting or location where clients were assessed was also related to both their geographic setting, as in the case of a rural client who travelled 45 minutes to another community for laboratory testing, and by care provider, as clients in midwifery care at times were assessed by phone.

Midwives and other providers frequently ordered ultrasound and laboratory

investigations to monitor or diagnose early pregnancy loss. For a small number of participants, the investigations to monitor symptoms or to reach a diagnosis were repeated several times over a period of days or weeks. In several cases, participants were reassured by bloodwork results to then receive a pregnancy loss diagnosis by ultrasound, which they found confusing and difficult. For most clients, ultrasound findings contained the most significant information related to their diagnosis and thus were a central part of their healthcare journeys. A few participants described challenges related to waiting for assessment and diagnosis, particularly in the ED.

# 4.2.3 Management and Treatment

Following diagnosis some clients were managed at home by their midwives, who provided care at a distance. Interestingly for midwifery clients, the home also emerged as a prominent site of healthcare in participants' healthcare journeys, as clients described receiving diagnosis, advice and support from midwives, waiting for referrals, or experiencing their physical symptoms of early pregnancy loss while at home.

For others, particularly those requiring medical or surgical treatment of their early pregnancy loss, considerable variation regarding where and from whom they received care was noted. Care settings where clients had their symptoms managed, sought, or were offered treatment included physician or obstetrician clinics, EDs and early pregnancy assessment units (EPAU). In addition to receiving care in multiple settings, participants at times also encountered several healthcare providers when receiving care or treatment for their early pregnancy loss. Changes from one provider to another were most likely to occur for the management and treatment of early pregnancy loss. While midwifery clients presenting with a spontaneous pregnancy loss were more likely to be solely managed by midwives, clients

requiring medical or surgical treatment of early pregnancy loss were referred by their midwives to family physicians or obstetricians for treatment.

The services or providers accessed by participants for the management of their early pregnancy loss were also impacted by the resources available locally. For example, two participants were referred by their physicians to early pregnancy assessment units (EPAUs), as these services were available in their urban communities. In comparison, a client in a rural setting travelled to a neighboring town to receive care from a local obstetrician.

Participants raised three main concerns as they navigated care for the management and treatment of early pregnancy loss. First, several participants reported concerns about wait times, as they described waiting days to attend referrals or receive treatment after diagnosis and felt this was too long. Second, some participants felt overwhelmed by both the number of care options and the challenges of navigating the steps required to receive care. Third, several participants requiring referral felt it was emotionally challenging to meet a new care provider that they did not have a previous relationship with.

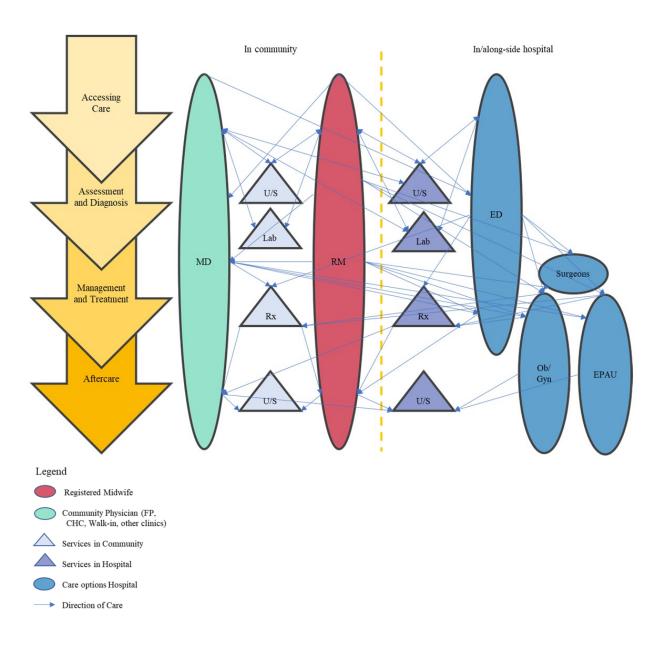
#### 4.2.4 Aftercare

Regardless of the care providers involved, the amount and content of aftercare received by women was highly inconsistent. While most participants attended a follow-up ultrasound assessment, this was not a consistent finding. Of those who attended an ultrasound as part of their follow-up care, a few felt they needed to actively request one or seek a care provider to order it. While some participants had follow-up visits with a primary care provider after early pregnancy loss, this did not appear routine. Only a few participants were either offered, referred to, or sought counseling or community supports after their loss. Several noted that specialized bereavement supports, or similar community services were not

available in their own community.

In summary, by mapping and comparing healthcare journeys, a complex picture emerges of how those experiencing early pregnancy loss move through and navigate their care within the Ontario healthcare context. For a consolidated healthcare map of services and providers that highlights the complexity of care pathways for early pregnancy loss in Ontario, see Figure 5.

Figure 5: Healthcare trajectories for early pregnancy loss



As healthcare journey mapping alone did not offer insight into what clients thought, felt, or said about their care, further insight was gained from how they described their experiences within the interview data. Interestingly, how clients felt about their care journey varied among participants and was often connected to their expectations. This was particularly noted for rural participants who considered traveling for diagnosis or specialist care, or accessing care from the ED, as quite acceptable within their setting.

There are a few overall observations that can be drawn from comparing client healthcare journeys. First, there was considerable variation noted in the pathways followed by participants in terms of where, and from whom, care was accessed and received. The variation among participant journeys appeared to be influenced by several factors, including but not limited to the services available, the type of early pregnancy loss, the primary care provider involved, and patient and provider preferences. For a few participants, their healthcare journey was further impacted by not having a primary care provider or health insurance. Comparing healthcare journeys also highlights the overlap between existing healthcare providers and services that provide some aspects of care for early pregnancy loss. Additionally, my analysis highlights the amount of movement by clients between healthcare services and providers, which hints at issues related to continuity of care and healthcare efficiency. Overall, my analysis of midwifery clients' healthcare journeys, coupled with participants' concerns about wait times, continuity and difficulties navigating care, suggests that the healthcare services for early pregnancy loss are not well-coordinated or streamlined. My analysis further suggests that midwifery care is both a dependent and an inter-connected healthcare service within the complex Ontario healthcare context.

# Chapter 5: Client experiences of midwifery care for early pregnancy loss

Having attended to the exploration of how clients access care and their care trajectories within the Ontario healthcare context, this chapter will explore clients' experiences of receiving care for early pregnancy loss from midwives. The analysis of client data revealed a considerable diversity in their experiences with midwifery care for early pregnancy loss. Clients described their strong thoughts and feelings about their healthcare experience, ranging from being very happy to deeply unsatisfied with the care they received. In this chapter I will discuss my findings from a thematic analysis of the interview data with midwifery clients. I identified four salient themes I felt both included the broadest range of experience by clients, but also made the biggest difference in how the care was experienced. These themes are as follows: Accessing care for early pregnancy loss; Continuity and following-through; Compassionate and supportive care; and Knowledge, information and choice.

## 5.1 Accessing care for early pregnancy loss

### 5.1.1 Accessing midwifery care

In the interviews, participants talked about accessing midwifery care for both pregnancy and for early pregnancy loss. While occurring separately from accessing care for early pregnancy loss, clients felt their experiences of accessing midwifery care for pregnancy had implications for determining how to access care for early pregnancy loss. Client participants frequently referred to the challenges of getting into midwifery care, including being on the waiting list to receive midwifery care, looking for a midwife by calling multiple local clinics, or not getting into care at all. Thus, not all clients described positive experiences related to accessing midwifery care in early pregnancy and surrounding pregnancy loss. Interestingly, participant accounts showed a considerable range of when their midwifery care was to start, from some practices taking clients

as early as 5-6 weeks pregnancy to others starting care at 11- or 12-weeks gestation. A couple of clients whose midwifery care was set to start after they experienced loss felt that their care experience would have been different had they had been in midwifery care, which was their preferred care option. A few participants also wished their care would have started earlier. Emma, who had a loss in her second pregnancy, questioned the practice of taking clients later into care because, for her, "the hardest part of a pregnancy is the first eight weeks, and that's the only time when you're alone". These examples suggest that the variation among participants' ability to start midwifery care was somewhat related to the community in which they lived and the local midwifery practice protocols about when clients start care.

#### 5.1.2 Being in Limbo

Once accepted by a midwifery practice, clients who had not had an intake appointment, and thus were not quite in care, often experienced feeling in limbo between care providers. For example, participants not quite in midwifery care reported feeling confused about who they should contact regarding their early pregnancy loss and who should be providing that care.

Teresa, who had midwives with in her first pregnancy, talked about how she did not seek any healthcare during subsequent pregnancy losses, as they were clinically uncomplicated. Confusion arose following her early pregnancy loss, as she recounted not getting an injection that her doctor felt she should have received. Teresa felt this "miss" occurred because her physician thought the midwives were looking after her care, including giving her the injection. Teresa's experience highlights the confusion among the clients and other care providers about who should do what, which can lead to clients 'falling through the cracks' between providers.

Lynne, who received early pregnancy care from a walk-in clinic prior to starting with the midwives, similarly struggled with being between providers when she experienced spotting at 8

weeks gestation. When she called the pager number of the on-call midwife, obtained by calling the clinic, the midwife she reached explained to her that she was "not actually in care", which Lynne felt was "new information". Lynne reported that the midwife was friendly and offered some advice, noting that "it felt like she was kind of doing me a favour, or just like doing something extra...[that] normally she would just serve the people who were clients". Lynne went on to discuss how being in limbo between care providers meant she felt she did not have a "care home" and that she felt responsible for navigating her own follow-up care at the walk-in clinic. "It was up to me to go in. It was up to me to continue to follow-up on these things, on even the ultrasound". Lynne ultimately felt like she was "in this in between phase... where you don't have a midwife... and no one's really looking out for your care".

Like Lynne, a small number of clients discussed how not having access to midwifery care meant accessing care from other services that were less preferred, such as emergency departments and walk-in clinics. One client, who, as new immigrant did not have health insurance coverage when her early pregnancy loss symptoms started, described how she looked online for uninsured clinics and eventually found an abortion clinic that could help her get a needed ultrasound. Thus, while midwives excel at providing access to their clients who are in care, these stories highlight that those who go through early pregnancy loss prior to starting midwifery care can experience feelings of being in limbo or confusion about how to access the care they need, and, at times, need to navigate services on their own, which is not always ideal for early pregnancy loss care.

### 5.1.3 Calling the midwife for early pregnancy loss

Clients further described how they accessed care from their midwives by pager or by calling the clinic with concerns, questions, or symptoms of early pregnancy loss, noting that how

to do so was often established at the first midwife appointment. For example, Leah, a rural client who experienced loss in her first pregnancy, remarked "I thought I was around 10 weeks pregnant, and had a small drop of blood...so, I contacted my midwife". For most, reaching their midwife was the first call they made to access healthcare when concerns arose. Contacting midwives for early pregnancy loss symptoms was not limited to those in care. A few clients who had been accepted into midwifery care but had not yet had their first visit also described calling into the clinic or paging an on-call midwife, thus seeing midwives as their preferred care provider for early loss.

It was also evident from their stories that clients strongly valued having pager access to their midwives, referring to it as "convenient", "straight-forward" and "fast". Scarlett, for example, called it "the best part" of midwifery care. Noting how having pager access exemplifies midwifery care, Shawna, who we met earlier, stated:

There's no such thing as paging or calling your doctor from home to get support like that. You could call health-line but then you're talking to someone that you don't know, and they don't know your symptoms and often the answer is to go to emerge anyway. I'd say doctors feel like they're past that arms reach, whereas the midwives, I felt like they were in my circle.

Shawna's feelings about her experience paging her midwives thus went beyond the ability to access them, but also showed this ready and timely access increased her sense of being supported during her loss.

Clients further described their comfort calling their midwives as well as their interactions with midwives once they reached them by pager. While most clients felt comfortable calling the midwife with any concerns, a few clients reported feeling more reserved about paging, not

wanting to be a bother. Despite any trepidation, most clients felt more reassured once they called. Emma, for example, described calling her midwife on the urging of her sister, after the onset of spotting. She said:

So, I called the midwife, and she was able to call me back in under 15 minutes, which was great. She walked me through the medical risks, and what I had to look out for, and we left the conversation sounding like, 'This is a very typical early miscarriage that is progressing normally, and safely, and basically everything is okay', which was simultaneously very comforting and I was pleased to know that nothing was abnormal.

She further reflected how the midwife she talked to was "lovely, cheerful, and optimistic".

Emma's story showed that access to providers can increase access to information, support and provide reassurance.

## 5.1.4 Maintaining Access

For some clients, access to and contact with their midwives occurred throughout clients' experiences of early pregnancy loss by means of phone, pager, and text messaging. For these clients, having this ongoing access increased their ability to ask questions as they arose, but also having ready access to a midwife increased their sense of safety when staying home. Some clients further accessed their midwives for care in the days following their early pregnancy loss. For example, Leah described calling her midwife five days after her loss, when she expelled a large clot. Even though her care was transferred to a local obstetrician for medical management, she felt her midwife was the appropriate provider to call. Thus, access to midwives, who are knowledgeable providers, made a difference in some clients' sense of safety and reassurance. It also appeared to contribute to a reduction in the use of other services or providers such as family physicians, obstetricians as well as care within emergency departments.

Not all clients, however, were certain about their ongoing access to midwives, citing confusion about whether they could access their midwife after they received an early pregnancy loss diagnosis, after a transfer of care took place, or at the end of care. A few clients also discussed the ambiguity surrounding the end of midwifery care, adding to their confusion about accessing further care from their midwives. These concerns will be further discussed in the next section addressing continuity of care.

### 5.2 Continuity and Following-through

Related to our discussion about access to midwifery care for early pregnancy loss, from the analysis of clients' experiences emerged the concept of being "followed" by their midwives throughout their care for early pregnancy loss. The notion of "following through" was further described by clients as related to both receiving care over time, including their aftercare, but also the guidance, support and healthcare navigation they received along the way. This particular theme showed largest range in client experiences, and starkest divide in what clients thought and felt about the care received.

# 5.2.1 Being followed or guided

Clients with a missed miscarriage describe a rang of experiences in how involved the midwives became and remained over the course of their early pregnancy loss. Some recalled their midwife following them through their whole experience, from assessment, diagnosis and management to aftercare. Leah's story about the care received in her first pregnancy particularly stands out as an example of the continuity provided by some midwives. After contacting her midwife with spotting at 10 weeks gestation, Leah's midwife ordered blood work and an ultrasound. Following the ultrasound, Leah's midwife came to the hospital to relay the diagnosis of missed miscarriage and to review management options. After choosing medical management,

Leah's midwife arranged the consult with a local obstetrician, but remained available to Leah by pager to answer questions and offer support. Following the loss and over a period of a couple weeks, Leah remembered getting frequent phone calls from her midwife to check-in regarding her physical and emotional recovery, which she found "really helpful". She went on to say, "it was nice to know that they were there to talk…someone that knowledgeable". Leah further described how throughout her care experience with midwives a relationship of trust was built which influenced her decision to return to midwifery care in a subsequent pregnancy. Leah's experiences were echoed by several clients who felt their midwife was "with" them throughout their pregnancy loss, and afterward.

Interestingly, feelings of being followed by midwives was not limited to those who remained exclusively within midwifery care during their early loss. Several clients who required additional care from providers or services felt their midwife played an important role as 'navigator' or 'guide' within the healthcare system, offering presence and support along the way.

### 5.2.2 Feeling Dropped

Some clients, on the other hand, reported not receiving as much follow-through or continuity from their midwives, resulting at times in feeling dropped. Feeling "dropped" by midwives was described by several participants at varying points along their healthcare journey. For example, a few clients who called their midwife with symptoms of early pregnancy loss were told to go to the emergency department for assessment and felt "dropped" when they did not receive any follow-up care or contact from their midwife afterwards. For others, being dropped occurred with the diagnosis of an early loss, most commonly a missed miscarriage. Marigold, who was among the more disgruntled midwifery clients, recounted feeling dropped by her midwives when she was told there was nothing they could do following her diagnosis of missed

miscarriage in the ED. Similarly, Scarlett, who was diagnosed with a missed miscarriage in her first pregnancy felt she was left to navigate care on her own. Scarlett relayed how after receiving her diagnosis, a midwife described the management options at a scheduled appointment. She felt the options included seeing her family physician, who typically could not see patients for several weeks, or seeing an obstetrician at a hospital, which at the time felt overwhelming to figure out given her state of "crisis". In the end, Scarlett decided to just let things "happen". Scarlett returned home and kept bleeding for three weeks without any further follow-up from her midwife before seeking further care at the emergency department. In reflection she had this to say about her midwifery experience, which led her to opt for obstetric care in her next pregnancy:

You were my care provider until the moment that I found out I was having a miscarriage, and then, probably not your fault, but you had to drop me, like, just right there. You couldn't do anything for me at that point.

While Scarlett acknowledged that her midwives' "hands were tied" by what care they could or could not provide due to their scope of practice, she would have preferred being placed in the "next seat", with more navigating support from her midwife.

Another common point in care when clients felt dropped by their midwives occurred at the time of consultation or referral to another care provider. Indeed, several clients required care for early pregnancy loss that was outside the scope of practice for midwives, necessitating referrals to other providers. Of these clients, most wished that medical treatment could have been managed by their midwives to reduce the need to see other providers and to improve continuity of care from their midwives. A few clients, such as Emelia and Scarlett, suggested that what midwives could do, and the care they received, impacted whether they felt midwives could

provide early pregnancy loss care. In both cases their experiences informed their decisions to seek alternate care for the management of their loss, and in Scarlett's case, subsequent pregnancies.

### 5.2.3 Receiving Aftercare (or not)

The aftercare, or follow-up offered to and received by midwifery clients in care varied considerably among participants, ranging from no aftercare to having physical assessments, ultrasounds, blood work and regular contact with midwives. While not all clients felt they wanted or needed follow-up care, there were a few clients who felt their care was again dropped, and that they did not receive the care they wanted. For example, following her loss, Adelaide expressed feeling her care with midwives ended abruptly, and was left wondering, "Oh, okay this is it then?". Similarly, a few clients said they would have appreciated a phone call, with most wanting an in-person visit for emotional support, closure and for an opportunity to ask questions about their recovery.

A couple of clients made observations about how midwifery care differs for individuals who have full-term pregnancies versus the aftercare following an early pregnancy loss.

Highlighting this difference in care, Marigold noted:

Once you've had a baby, they call you like every other day, or they come visit you, and they give you all sorts of support for that. I feel like that same level of support would have been helpful for [me]. I already had an appointment and had a later first trimester miscarriage. So, I guess for people who have already had an appointment, that's what I would expect. They've already met me. I would have appreciated having that follow-up care.

Marigold's comment highlights that how clients feel about the lack follow-through or aftercare can be related to their expectations of care from their midwives.

Overall, how clients felt about the follow-through of midwives seems somewhat related to their expectations of their midwives, which were tempered by whether they felt care was needed, or whether they had access to other acceptable care options.

## 5.3 Compassionate and Supportive Care

During the interviews, participants shared how they experienced their loss emotionally and reacted to their loss. Considerable variation was noted among the clients' responses to their early pregnancy loss, ranging from those who described it as just getting their "period", to others who were "devastated" by the loss of a baby. Most, however, found the loss of their early pregnancy difficult emotionally. Understanding clients' reactions to their losses is important because how clients felt about their loss was strongly related to their needs and expectations regarding compassionate support from care providers. Several sub-themes presented here describe how feeling supported or not throughout their midwifery care made a difference in how the clients felt about their care.

### 5.3.1 Receiving sensitive and compassionate care

Several clients noted that midwives attended to their care with sensitivity and compassion, which was experienced in different ways. For some, it involved the use of compassionate language, or the way midwives spoke. Some clients, for example, described their midwives as "calm", "compassionate" or "caring". Clients relayed that how they were received or the manner in which information was shared by midwives was particularly important when they were first reaching out with concerns, or when receiving a diagnosis or being relayed bad news. Others felt midwives showed compassion by expressing awareness of the timing of

conversations when relaying information or diagnosis, and by giving space and time for clients to make decisions.

### 5.3.2 Acknowledging loss and its meaning

For several clients, compassionate care further involved both acknowledging the early pregnancy loss and attending to the emotional aspects of care. Clients who described more positive experiences receiving midwifery care felt their midwives sensitively acknowledged that the pregnancy loss may have been difficult. Simple gestures from midwives and midwifery clinic staff, such as cancelling upcoming visits or sending a note by mail or email, went a long way for these clients. For others, the loss was acknowledged when midwives attended to their emotions. For example, some clients reported being asked about their emotional state and being offered online or community resources related to pregnancy loss or grieving, including referrals to counseling. Mary, who received early pregnancy care from both physicians and a midwife, had this to say about how her midwives both acknowledged her loss and attended to the emotional aspects of care:

I called and spoke with them a few times afterwards, and they ended up...sending me and my partner a condolence card, which was really nice. And they sent pamphlets about counseling and different resources in the area that were available, which I really, really appreciated. I still have the condolence card. It just meant a lot to me that they would do that and think about us.

For Mary, this small gesture by midwives acknowledged the loss and its emotional impact.

Clients who received aftercare also appreciated the opportunity to talk about their emotional recovery, feeling it helped them cope with their loss.

### 5.3.3 Compassion within philosophy of care

In some cases, the philosophy and approaches of midwifery care pertaining to pregnancy loss were further connected to receiving compassionate support. For example, some clients appreciated hearing that the loss they were experiencing was not something medically urgent, and others that pregnancy loss is a common occurrence and a part of pregnancy that happens to some people. Lynne, for example, talked about how her midwives communicated with her about early pregnancy loss:

I think that the advice that I received from midwife was way better than the advice I got from the walk-in clinic, or certainly from Tele-health, [where] miscarriage is a medical thing. It's not an illness. You don't have to like pathologize it. It's just a thing that happens. And so, for the midwife to be able to give me that perspective was so helpful, because she's probably seen lots of people who've had miscarriages. It was great to have that sense [that] 'this is a normal thing'. It just helped me a lot to not feel extra, like, sadness, and extra emotion and pain around it.

Lynne noted that having her early pregnancy loss treated as something that was "normal" helped her frame her loss and cope with it. Lynne also shared that having her early pregnancy loss treated as a non-emergency by the midwives helped her in making the decision to avoid seeking unnecessary emergency care, which she felt would have been "traumatic". Lynne further described how being able to stay home meant she and her husband could have "some time together", to "grieve in that moment together" in a way she may not have had should she be in an emergency department. Thus, for Lynne, the care provided by the midwife was also linked with a space in which it occurred, which she felt helped to reduce trauma and give space for an emotional response.

### 5.3.4 Not going far enough

While some clients felt they received compassionate care and emotional support, other clients felt their midwives could have gone further to attend to the emotional aspect of their loss. Marianna, for example, recounted that she felt that the care she received from her midwife focused more on the physical aspects of the loss and recovery rather than the emotional. Reflecting on her own expectations, Mariana pondered whether she was expecting too much when she did not receive the emotional support she would have liked and whether it was actually the role of midwives to attend to the emotional aspects of care. Emma, who had frequent contact with her midwife from diagnosis to the completion of her loss, similarly felt she would have appreciated aftercare for emotional "closure", due to how traumatic her experience was.

Describing her experience, she said:

I've been thinking about this a lot. I would have wanted a follow-up phone call...or an in-person visit, or something to provide some closure to the loss... I was far less likely to ask for something, than to accept something being offered. I think ... if she had said, "Would you like to come in tomorrow?", I would have said, "yes". But, if she said, "y'know, call me, um, if anything comes up", I wasn't likely to call her or anything, knowing how busy and chaotic a midwifery practice can be. And the last thing I wanted to do was to be a burden. But at the same time, I think I probably wanted something more than what I received.

Emma's account highlighted that clients may not know what they need when they are experiencing early pregnancy loss and may not always be inclined to ask for further care. While not all clients had the same expectations of emotional support or compassionate care from their

midwives, for some, it was part of their decision to utilize midwifery services, feeling that midwives exemplify this type of supportive care.

## 5.3.5 Minimizing Loss

When clients' expectations of compassionate care were not met they were more deeply unsatisfied. For example, a small number of clients felt the attitudes and actions of their midwives were less caring. Marigold, whose care I reviewed in detail earlier, felt her midwives were at times "flippant" about her loss, seeing it as "no big deal". She, among others, attributed the coldness of her midwives to the frequency in which midwives hear about early pregnancy loss. Marigold further described rather emotionally that she wished her midwives would have offered more reassurance that what was occurring was "common", and that she "didn't do anything wrong". Thus, while most clients appreciated their midwives treating early pregnancy loss as a common occurrence, they also did not want their loss minimized in the process, seeing their midwives as ideally playing a key role in providing emotional support.

Overall, client experiences suggest that compassionate support, in its variety of forms, is needed and wanted. Clients' needs and expectations of compassionate support during early pregnancy loss were often related to how clients felt about their loss. While some clients felt very supported by their midwives, clients who felt unsupported reported feeling more traumatized, had a greater distrust in health care providers, sought care elsewhere, and had unresolved emotions that sometimes carried into subsequent pregnancies. Additionally, the variation among clients' needs and expectations suggest that an individualized approach to care may be appreciated by clients.

## 5.4 Knowledge, Information and Choice

Participant knowledge and their informational needs prior to and during early pregnancy loss represented a dominant theme emerging from the data. Clients spoke of their information needs in terms of their own knowledge gaps prior to the loss, but also what information was needed along the way to know what was happening, what to expect, and what decisions to make about their healthcare or management options.

### 5.4.1 Clients knowledge prior to early pregnancy loss

Participants' reported knowledge of early pregnancy loss prior to their own experiences varied considerably. Those who had an initial midwifery appointment or previous midwifery care reported having some awareness about reasons they might page a midwife, which also included symptoms of miscarriage. For example, Emma reported feeling "well-prepared to know what was normal or not". Additionally, participants who had gone through fertility treatments, had prior miscarriages, or knew someone close who had experienced miscarriage reported greater knowledge of early pregnancy loss. For example, Emelia, who experienced a missed miscarriage in her first pregnancy, reflected on her knowledge ahead of her loss:

I had done a lot of reading, and I kind of understood how like my cycle worked, and I knew what symptoms to expect with the pregnancy. I had a lot of friends who either were parents or...had actually gone through miscarriage before, so I had a good sense of the risks of early pregnancy too. In the back of my mind, I knew, 'It's early. Take your time, and don't get too excited because miscarriages happen. They're pretty common.'...I had that kind of, not a feeling that it was going to happen, but just an awareness that it was possible.

Thus, some clients felt more prepared than others for the possibility of an early pregnancy loss based on their knowledge and awareness.

### 5.4.2 Receiving information, being informed

Recalling their experiences, clients talked about the role their midwives played in providing them information. For example, clients who called their midwife with early pregnancy loss symptoms received information about what may be happening, their options for assessment and diagnosis, what to expect from an emergency department visit, and also what symptoms would be abnormal and require urgent medical attention. Interestingly, descriptions of the parameters provided by their midwives as related to normal blood loss, such as filling a pad in one hour being concerning, were relatively consistent among clients. Those receiving diagnosis following an ultrasound further reported detailed explanations from their midwives on the management and treatment options available.

Clients further discussed how the information provided by midwives helped them make decisions about navigating their healthcare options for both assessment and treatment of early pregnancy loss. Some clients felt they would receive more timely or urgent assessment in the emergency department after seeking the advice of a midwife. Conversely, a few clients reported deciding to stay home after talking with their midwife about their care options. Additionally, clients who were given detailed information about treatment options could make individualized decisions about the most appropriate care setting or management option based on their needs and preferences. Thus, well-informed clients felt more confident and supported in making decisions about their care.

### 5.4.3 Identifying Information Gaps

For many clients, their understanding of their information needs changed with their early pregnancy loss – meaning they did not know what they wanted or needed to know until faced with early pregnancy loss symptoms or diagnosis. While clients were generally satisfied with the information received from their midwives, there were a few gaps in information that clients felt could be expanded upon by their midwives and other care providers. First, a few clients felt they would have liked more information on what to expect regarding their symptoms, especially surrounding blood loss and pain. Clients undergoing medical management of early pregnancy lsos reported feeling inadequately prepared for their associated symptoms, which is an issue for the consultants prescribing the medication, but also pharmacists dispensing it and midwives offering supportive care. Leah, for example, reflected on how she felt when going through her loss, which was managed with medication:

I don't know if I fully... not that I didn't understand what would happen, I don't think I understood the level of pain that would [accompany] it. And, like, I think emotionally, when you are going through that, I don't think I was fully prepared for it.

Leah's comment showed how she not only felt unprepared for the physical symptoms, such as pain, but also for the emotions that accompanied her early pregnancy loss. Adelaide, whose case we reviewed in the previous chapter, felt her providers where not getting "real" with her about what to expect. In reflection, she noted that "the lack of information, and lack of preparedness... created more fear...than the actual incident". Thus, the amount of knowledge and preparation regarding symptoms had implications for clients' level of confidence in their ability to handle the symptoms or remain home.

Another gap in client knowledge that was discussed frequently was related to what are commonly referred to as the products of conception. Several clients described not being confident about what to look for, but also how to tend to, or handle, these remains. Shawna, for example, talked about how she carefully saved several blood clots to plant in her yard until she, with the help of a nurse, identified what was more likely fetal tissue. Mary, who went online to learn about her options, noted that "a lot of people talked about burying it somewhere in their yard. It was just very sad to read all these stories of women who really had no idea. Some people flush it down the toilet". Mary, pointing out that miscarriage is a topic of cultural taboo, noted that "it's just this underground thing that nobody ever talks about". Several clients felt midwives could play a more prominent role in ensuring this information was available.

The largest gap in client knowledge was noted for those experiencing a missed miscarriage. Emelia, for example, described feeing caught "off-guard" and "devastated" by the diagnosis. Several clients further relayed that they had never heard of missed miscarriage prior to their loss. Adelaide, for example, explained how she thought she was "out of the danger zone" because she had not experienced any typical symptoms of early pregnancy loss. While several clients would have appreciated knowing in advance that early pregnancy loss was a possibility, there was a lack of consensus among clients on when the possibility of miscarriage should be introduced by midwives or other care providers.

Clients further highlighted gaps related to their informational needs when navigating care options outside of midwifery care. For example, a few clients relayed feeling confused about how to proceed to the next steps in care and about the roles of their providers when referrals and transfers of care occurred. Other clients noted that it wasn't always the content of the information

that impacted their ability to make choices about their care, but also the timing or manner in which it is delivered, that was the issue.

### 5.4.4 Seeking information elsewhere

In addition to the information received from their midwives, most participants described seeking information from other sources. In some cases, participants sought information from other individuals. Finding gaps in her knowledge, for example, Shawna sought information and guidance, including what to expect regarding pain and bleeding, from friends who had experienced early pregnancy loss. At other times, clients reported seeking advice from an alternate care provider when they were not satisfied with the information they received from their midwives.

Almost all participants sought further information online at some point during the process of their early pregnancy loss and for different reasons. Some participants went online to inform themselves before paging their midwives with concerns and to help them decide if their concerns were reason to page a midwife. Participants additionally reported frequently seeking information related to the risks of loss, their symptoms and diagnosis, management options, and symptoms. For some, going elsewhere for information was an empowering process and for others a way to supplement scant or missing information they received from midwives and other care providers. Clients additionally described going online to normalize their own experiences, by seeking out information on the rates of loss, but also to connect with online forums or communities where others had experienced early pregnancy loss. Clients, by and large, reported a paucity of credible information on the specifics or details of what to expect in terms of symptoms (pain/bleeding) and what they might see during the process.

#### 5.4.5 Culture of Silence

Within clients' discussions about their knowledge and information needs, many identified that their lack of knowledge was situated within a larger cultural context, not solely related to their healthcare experiences. A few participants connected what they felt was a culture of silence around early pregnancy loss with the existence of stigma, as well as shame and blame surrounding their pregnancy loss. A few clients felt that there was a cultural shift happening, reporting that more people around them were openly talking about their own early pregnancy losses, and that it was no longer the taboo topic it had once been. Conversely, a few participants were not comfortable talking about their experiences with family or friends, for example, feeling it was not a topic they or others felt comfortable discussing. In general, most felt that an increased public awareness of the rates of loss, missed miscarriage, and information on how to support those who have experienced loss would be helpful. Several clients felt midwives could play a role in raising cultural awareness to rid of the culture of silence they experienced around early pregnancy loss.

In summary, as participants described their experiences of receiving midwifery care for early pregnancy loss, several overlapping themes emerged. These themes helped to identify what made a difference to clients in terms of how they experienced the care they received. Overall, clients were seeking support through their early pregnancy loss, which included receiving information, access, and compassion as well as having an ongoing relationship with a provider. Thus, the desire for compassionate support in its many forms represents a cross-cutting, overarching theme.

It is understood from these findings that client perceptions of their care were entwined with the meaning they attached to their loss, but also expectations they had about their midwifery

care as a whole. While some clients were very satisfied with their care, others noted a mismatch between their expectations and the care received, which resulted in disappointment.

Additionally, while clients would have preferred to receive more care from their midwives, and at times wished their midwives could do more, they appreciated the guidance and navigational support as they moved through the healthcare system. Clients largely saw their midwives as knowledgeable providers, who were their first choice for providing early pregnancy loss care. Clients were less satisfied if they did not receive the individualized, compassionate support they needed during this time, leading them to seek care elsewhere and question whether midwives are the most appropriate provider for early pregnancy loss.

# Chapter 6: Midwives' experiences providing early pregnancy loss care

To further understand and situate the experiences of midwifery clients within the healthcare context, I examined the experiences of midwives providing early pregnancy loss care. Similar to the findings derived from interviews with clients, I found that how midwives described the care they provide for early pregnancy loss varied among participants, in content and amount. For example, how much miscarriage care was undertaken or referred elsewhere, and how much involvement midwives had following referrals or in providing aftercare varied considerably. Also, while some midwives described providing this care "routinely" (i.e. a few cases per month), others provided this care infrequently, or "sporadically".

Within the interview data, midwives described a range of experiences that included their direct interactions with clients, their experiences with other providers and services when providing client care, and their subjective feelings about their experiences. The midwives additionally reflected on the impacts their model of compensation, education, funding, and scope of practice have on their experiences providing early pregnancy loss care. To best capture and describe these rich findings, I summarize the data in four salient themes which describe midwives' experiences of providing early pregnancy loss care: Feeling confident, being equipped; Deriving satisfaction and meaning from providing early pregnancy loss care; Providing early pregnancy loss care within the healthcare context; and Feeling valued and recognized as providers of early pregnancy loss care. The first two themes presented relate more to the subjective experiences of midwives, whereas the last two themes further situate midwifery care within the broader healthcare system.

#### 6.1 Feeling Confident, Being Equipped

Most midwife participants felt that midwives play an important role in providing early pregnancy loss care for their clients, given their particular expertise and skill set. Harriet, an urban midwife with almost 15 years of experience, noted that midwives "have [the] expertise...to really provide individualized...and client-centered care, and help [clients] navigate the system". Despite being well-positioned to provide this care, not all midwives felt equipped or confident to offer care for early pregnancy loss.

Morgan, an early-career, urban midwife, shared her enthusiasm for providing early pregnancy loss care, saying "I feel super-confident. I wish I could do more. I wish I didn't have to refer people. I wish I could be the person who just manages it start to finish." For Morgan, and for several other midwives, confidence in their knowledge and skills for providing this care was accompanied by a desire to offer more care for their clients than what they currently were providing. Morgan's case also highlights that one's confidence in providing early pregnancy loss care is not necessarily attributable to a midwife's years of clinical experience.

Despite most participants feeling confident in the ability to offer early pregnancy loss care, there were a few aspects where some midwives felt less certain about their knowledge and skills. For example, several midwives noted they were not trained counsellors, and thus had insufficient expertise to support clients through grief. A few midwives described how having a lack of confidence in one's knowledge and skills has implications on how they practice. Beatrice, who has been practicing for over a decade, shared that at times she feels she is "shying away" from providing the emotional support or information she imagined her clients want or deserve. She also described how her miscarriage care can feel at odds with the other care she provides within the midwifery model. She said:

When I think about the ways that we're sensitive to all sorts of other circumstances that comes up in client care, I feel like early pregnancy loss is one thing I don't feel like I'm necessarily well-equipped, or that I'm really tackling with the same depth that it warrants.

Beatrice's comment highlighted the relationship between her confidence and her knowledge and skills in providing early pregnancy loss care. A few midwives further described how they felt less confident with identifying what is considered to be clinically "normal" when it comes to early pregnancy loss symptoms, noting they feel more comfortable with identifying abnormal symptoms, or when a clients should seek emergency care. Beatrice thought that sometimes the information she gives to clients experiencing pregnancy loss is "very broad" and "generic", and at times the care she gives is more "bare-bones", identifying how the gaps in her knowledge have implications for her practice.

Another midwife, Hannah, who recently attended a training on the management of early pregnancy loss, suggested that midwives do not just have to be confident in the clinical aspects of care, but also how to navigate the system so their clients can get the care they need. When providing care in remote settings, she identified that her "unease" more often comes from "logistics", and the worry that clients will not get the care they need. Thus, midwife knowledge and confidence extended beyond the immediate care of the client and were sometimes tied to how to navigate and access other services required.

As midwives' confidence appeared very related to their knowledge and experience, it should not be surprising that the education and training of midwives featured prominently in this context. A few midwives felt their experiences within their education program helped develop

the knowledge and skills required for providing early pregnancy loss care. For example, Marie, a mid-career, rural midwife, described the valuable exposure she had during clinical placements:

I had the experience of doing a lot miscarriage care during my training...so I probably graduated with more expertise than a lot of midwifery students graduate with, partially because I was here, in this practice, but also even in my clerkship practice, which was in a more urban centre, they also did a lot of pregnancy miscarriage care...[that] I was directly involved with. It never occurred to me that it wasn't part of my scope.

Marie acknowledged that her exposure and experience can be attributed to the midwifery practice groups she had practical placements within but also identified that there is considerable variation in student experiences prior to graduation depending on where placements took place. Now, as a clinical preceptor, Marie feels "it's a really big loss" that care for early (and later) pregnancy loss is not "adequately covered" in midwifery education.

Several other midwives discussed how the lack of attention paid to early pregnancy loss in their studies meant they felt ill-equipped to provide that care following graduation. Jasmine, a midwife in her second year of practice, reflected on her experience as a student and new graduate and noted:

I feel like when I was a student, I didn't have very much experience. It doesn't always prepare you super-well. I did get a job at the clinic where I had my senior year, so, you have the mentor you're able to ask "What do I do with this person who's having these symptoms? or How can I do a referral?". I don't think I was that well prepared [to provide early pregnancy loss care], to be honest, coming out of school.

Jasmine's experience connects the lack of exposure as a student with being less prepared in the future, but also highlights the important role of mentoring relationships within and following

midwifery education. Claire, who received her midwifery training elsewhere, connected midwifery education in the province to how midwives provide care, when she said:

I've had a lot of friends going through the program and [have] been disappointed at how little [early pregnancy loss] education they get. [When they] are inexperienced or unequipped to manage it, [they] don't manage it. They send people to emerge, or their family doctor, or an OB, or whatever. And then, that's just a cycle. They're not managing it, so they don't learn, so they don't feel comfortable, so they won't manage it. Like, it's just a cycle, and never get out of that.

Other participants similarly noted that midwives with less experience or confidence may rely more on other service and providers. Marie, contemplating what she feels is a trend within the profession to provide less early pregnancy loss care, wondered if there are implications on how clients see midwives' role in the early pregnancy loss care provision. She was worried that clients would view their pregnancy loss and subsequent pregnancies as higher risk requiring medical care, instead of seeing early pregnancy loss as part of a normal pregnancy, situated within midwifery scope of practice.

A few midwives acknowledged that being ill-equipped is not singularly a result of their education or their current practice culture, but rather is part of a larger health context where training or resources for early pregnancy loss are not prioritized. Several midwives pointed out that resources that they could use as reference materials, such as clinical practice guidelines on the management of early pregnancy loss, were also lacking. Some midwives felt this is an issue facing other healthcare providers who similarly struggle to provide aspects of this care. Petra, an early career midwife working in a largely rural area, reflected that emergency physicians in her community similarly lack exposure and training to attend to those presenting to the ED with

early pregnancy loss symptoms. "They don't necessarily know what they're doing. They know what to do with your broken leg, but not with your psychological crisis", she reflected. More encouragingly, Petra went on to say that, fortunately, "it doesn't take that much experience to feel confident with...what the normal range of early pregnancy loss [is]", meaning that with training and support, providers, including midwives, can increase their confidence to provide this care.

The midwives were notably self-reflective and appeared to take personal responsibility for their learning and knowledge post-graduation. Several midwives noted that they either had an interest in learning more about supporting their clients through early pregnancy loss and its management or had found ways to better equip themselves to provide this care. Thus, postgraduation ongoing professional development was important to this group. A few midwives discussed increasing their knowledge in several ways, including asking clients about their physical and emotional experiences of pregnancy loss, researching online, and by taking additional clinical or bereavement training, such as those offered through their hospitals or the Pregnancy and Infant Loss (PAIL) network. Notably, the way midwives described how they increased their knowledge to provide early pregnancy loss care, situated the onus to receive this training on the midwife. One midwife, Claire, additionally pointed out that most related trainings were not coordinated by midwifery-related organizations, feeling strongly that "midwives should be learning from midwives" to strengthen and maintain the unique knowledge and skills held within the midwifery model of care. Claire's comment highlighted the challenge of balancing the need for midwifery integration and professional collaboration within the healthcare system while maintaining a midwifery-specific model of care.

## 6.2 Deriving satisfaction and meaning from providing early pregnancy loss care

Most midwives interviewed felt they derived some, albeit varying, satisfaction or meaning from providing early pregnancy loss care. For some, satisfaction was derived from seeing the positive impact their care had on clients, noting how even small gestures can make a big difference for their clients. For example, Beatrice reflected on a time when a client was grateful for a phone call that took her only moments. The impact that phone call had on that client resulted in strengthening their client-provider relationship in a future pregnancy, but also impacted Beatrice's resolve to continue offering more early pregnancy loss care. Other midwives described offering clients what they felt was an alternative to care provided in other settings, such as emergency departments. In this sense, deriving satisfaction was linked with making a difference for clients, or social justice work, which appeared to further motivate some to provide early pregnancy loss care.

Some midwives additionally talked about how their own experience of providing care felt mutually beneficial and meaningful. Claire, meeting the client for their intake pregnancy appointment after this client experienced early pregnancy loss, reflected:

There has been isolated incidents and they have been really meaningful to me, and I learned a lot through them. I actually wish it was a much more frequent part of my care. I wish every client who called and said "Oh, I don't need your care anymore, I had a miscarriage last week", that I could advocate within my practice... to say 'Why don't you come in anyway'...It might be helpful for them, and helpful for us.

In Claire's view providing early pregnancy loss care has reciprocal benefits, through both the emotional connection and the insights she gains from providing this care for her clients, which further contributes to her motivation to continue providing this care.

For other midwives, satisfaction and meaning were derived from being part of a group or organization that was collectively offering a certain philosophy of care. Marie described a level of pride that comes from providing pregnancy loss care within her practice group, which has worked to build "expertise" in providing this care.

There's many midwives in our practice who are very strong proponents of providing quality miscarriage care, even if those services have analogous services in the community....I think as a practice group, we philosophically have a different way of looking at pregnancy loss, and it's something we actually are very, I don't want to say "proud of" in a weird way, but certainly something we feel like we are developing an expertise in. Even as the practice has grown and changed, it's something that I think new midwives joining our practice have found as a...very satisfying part of [their] work, because it's really taking care of people...when they really need care.

Marie's reflections highlighted how a practice culture of taking care of others during early pregnancy loss can foster satisfaction for those involved in providing that care. She also underscored the role of mentorship in building a culture of care that new midwives can also derive satisfaction from.

A few midwives noted that deriving meaning or satisfaction from providing early pregnancy loss care was essential when providing care. Harriet, for example, noted that "Unless you are getting personal satisfaction out of it, or a client's really needing your help, you don't have that incentive to really put in that extra time". While Harriet personally felt that it was "worth going above and beyond" for her clients, she noted that some midwives may not be as motivated to provide this care given certain challenges, which will be further described below.

While not all midwives described deriving meaning and satisfaction from providing early pregnancy loss care, my impression, informed by the data, is that for those who derived more meaning from their work also viewed the work they do and the care they provide more positively. In addition, those who derived the most satisfaction and meaning identified the greatest client need for midwifery-led care for early pregnancy loss, or felt they were filling significant gaps within the healthcare system. This group of midwives also seemed more likely to offer their clients earlier and more continuous care, to want to provide more care, and were the most bothered by their inability to meet their clients' needs. Conversely, the midwives who did not talk about deriving satisfaction from providing this care were more likely to see it as something "extra" they have to offer to their clients. Notably, these midwives were more likely to work in settings where there were other services available to meet the needs of clients, which could have taken away some of the need or pressure to provide early pregnancy loss care. Thus, in some ways, midwives' motivation and how much meaning they gained from their work can be tied to the needs of the clients, and whether they are being met elsewhere.

## 6.3 Providing early pregnancy loss care within the healthcare context

During the interviews, midwives described being enabled or challenged in their ability to provide the early pregnancy loss care that met the needs of their clients. Midwives connected their ability to provide care both to their autonomy as primary care providers, but also to the challenges or constraints that hindered their ability to do so.

## 6.3.1 Being autonomous primary care providers

Midwives reported having a certain level of autonomy to make individualized decisions about providing care to their clients. Morgan, who has been practicing for over 2 years in an

urban setting, connected her autonomy and her ability to tailor her care to the needs of clients, when she said:

I feel like I have the liberty to make my miscarriage care look whatever I want it to look like, in my current context. So, aside from [not] being able to prescribe the medication, I have the liberty to go and do half a dozen home visits with this client, if they're really struggling, or if the client is worried that they have an infection because of retained products, I can go do an assessment and determine if I think they need to be seen by someone else. I don't think I'm restricted in how I provide care.

This sentiment was echoed by several midwives who described providing individualized care to meet the diverse needs of clients. For example, in addition to offering more emotional support for clients who appeared to need it, some midwives provided home assessments for clients without transportation or health insurance to improve access or reduce out-of-pocked expenses.

Despite being autonomous primary care providers, midwives discussed facing challenges or systemic constraints related to their ability to provide the care they wanted, as further outlined below.

#### 6.3.2 Being constrained by work context

Several midwives felt their work context was not always conducive to providing the early pregnancy loss care they wanted. Citing competing demands on their time, such as scarce clinic visit slots, hectic schedules, and large waiting lists, midwives reported needing to make decisions as individual providers but also within practice groups about how much early pregnancy loss care to provide. For example, some midwives felt, due to their heavy workloads, that they often needed to prioritize providing care to clients who were further along in their pregnancies. Others shared strategies either their practice or other practice groups took to reduce the impact of clients

requiring early pregnancy loss care on their workload. For example, midwives described how some practices intentionally book clients later (i.e. 11-12 weeks) to reduce the work associated with providing early pregnancy loss care. Other practices limited the visits available for clients who were no longer pregnant.

Highlighting further variation among midwives in the provision of care for early pregnancy loss, a small number of midwives felt that their desire to provide this care in a certain way was further challenged by either their practice culture or protocols. Chalking up the difference among midwives within the same practice to midwives' comfort, experience, but also workload and compensation, those feeling at odds within a practice group often felt they wanted to do "more" for their clients than other midwives they work with.

Of those midwives who wanted to provide more early pregnancy loss care, a couple had different visions of how they personally would like to work or provide this care in their communities. For example, a few midwives suggested they would like to act as a referral service for other providers, including for midwives or ED physicians who may not want to provide as much early pregnancy loss care. Several midwives identified that how the profession is currently organized and funded pose challenges for innovating new care models, but that newly funded Expanded Midwifery Care Models (EMCM) may create some unique opportunities for other models of care to emerge.

## 6.3.3 Being constrained by scope of practice

How midwives felt about their ability to provide the early pregnancy loss care was strongly connected to regulations surrounding their scope of practice and their pharmacopeia.

While not all midwives felt limited by their scope of practice, almost all the participants felt that expanding their scope of practice to include medical management of early pregnancy loss would

be an asset. Midwives thought it would make care provision easier and more convenient for themselves, clients, and other providers, with the added benefits of improving continuity of care for their clients. When asked about her ideal model of care for early pregnancy loss, Roxanne said the care "would be full-circle. We've diagnosed it, treated it, supported her emotionally, and educated her about future".

Despite the interest in changing regulations related to scope of practice, midwives feared these changes would be met with contempt from other health care providers. For example, midwives discussed how, at times, they already receive push-back from physicians regarding their scope of practice or skill set. Mia reflected that within her community physicians are "sort of resistant to expanding midwifery scope". In her experience, there is a sentiment among some physicians that the expanding of midwifery scope reflects "medical creep". Jasmine, who frequently refers clients to her local hospital, felt similarly that despite "good relationships with the obstetricians" she was not certain they would "necessarily [be] happy to have midwives providing care that typically they provide". Thus, the push-back from other providers, particularly physicians, was seen as an ongoing challenge related to expanding the midwifery scope of practice.

Some midwives also expressed concern that an expanded scope of practice would involve doing more work on top of an already heavy workload. Thus, while there was near consensus that an expanded scope would be an asset in some ways, there was not consensus among the midwives in their desire to provide or do "more" early pregnancy loss care.

## 6.3.4 Referring Care to Providers and Services

Closely connected to discussion about the midwifery scope of practice was their current need to direct and refer clients to other providers and services. Midwives' experiences of

referring clients who require care outside of the midwifery scope of practice, and how they felt about them, varied among participants. On the one hand, some midwives felt that, when available, referring their clients to Early Pregnancy Assessment Units (EPAUs) made their jobs "easier". Several midwives also acknowledged that the care they provide is analogous to other care options available to clients, which also made referring clients to these services as an acceptable option. On the other hand, midwives found referring care to other providers time-consuming and at times cumbersome. Roxanne, who felt limited by her scope of practice, acknowledged that she often felt like she had to "jump through hoops" to get clients the care they needed. This sentiment was echoed by several other midwives. Additionally, some highlighted the increased workload associated with navigating care for clients without health insurance or in contexts with fewer services, such as in rural and remote communities.

Midwives further pointed that referring care was not only an inconvenience for them, but also for the clients and the providers they refer to. Mia, reflecting on how care is delivered in her community said, "I don't think it's a nice set up the way it is now. I think we could be providing a smoother service for...client[s], and cheaper for the healthcare system." Relying heavily on other providers for referrals also meant midwives at times felt more like a "burden" on the healthcare system.

Midwives noted that the care that they were able to offer their clients was strongly connected to the providers and services available at the local level. For example, the sporadic availability of consulting providers with the required skills, particularly in rural and remote communities, impacted midwives' ability to get clients the care they needed or wanted. Petra, who practices rurally, discussed how the only physician who provided surgical management of early loss was retiring, leaving a large care gap in her community, changes that will require

clients to be referred for that care elsewhere. The preferences of consulting physicians also played a role in the care options available locally. For example, while Mia noted that in her community the physicians rarely offer surgical management due to their strong preference for medical management, Roxanne noted that in her community several physicians would not prescribe medical management. In both cases, providing early pregnancy loss care required considerable advocacy work to have their client management choices fulfilled and respected.

In general, there was a consensus among midwife participants that finding ways to increase midwives' ability to care for clients, by taking into consideration their scope of practice and resources at their disposal, was important.

## 6.4 Feeling valued and recognized as providers of early pregnancy loss care

As midwives shared their experiences of providing early pregnancy loss care, one particularly dominant theme that emerged from the midwives' data, was the importance of being valued or recognized as healthcare providers for early pregnancy loss, by clients, other providers, and within the broader healthcare system.

## 6.4.1 Being valued and recognized by clients and communities

Most midwives interviewed felt their skills, knowledge and expertise were sought out by and highly valued by their clients. For example, several midwives discussed how clients frequently page them with concerns related to early pregnancy loss, and how they were often the first call clients made. Marie, who works with many Old Order Amish or Mennonite clients, shared that:

A lot of times people call us and they'll say, "Oh, I asked my mom what I should do, and she said I should call you", and that's actually just a sign that we've provided this care for generations in that community, [and] that when people do have a miscarriage,

they ask for help from their close family members, and the suggestion is always to contact us.

Marie's experience in taking calls from clients further indicated how midwives in some communities have built up their reputation as the person to call for this care over time, and that for many clients calling the midwife is "the norm".

However, not all clients call midwives first, according to those interviewed. Midwives acknowledged that clients sometimes do not call them, or sometimes present to the emergency department prior to paging. Midwives cited the convenience of being assessed in the emergency department as the primary reason clients may seek care elsewhere, but also noted that not all early losses require clinical care. Additionally, several midwives highlighted the role new or existing client-provider relationships play on client choices when seeking care for this early pregnancy complication. Harriet suggested some clients, such as those returning to care, may have more comfort in calling midwives with symptoms, commenting:

We've told them that they could [call]. In those in situations, it tends to probably be more repeat clients, or clients that feel they understand they can access us. There's definitely people that I wish, 'Oh, you could have called us'. Sometimes you just haven't had a lot of time to get to know that person and explain all of the reasons to call us, and when. And because we're in shared-care, I might have done the initial appointment, but then the person they are talking to is my teammate, who they've never met.

Harriet also pointed out that building relationships with clients in early pregnancy can be challenging, especially when midwives and clients have not met prior to arising symptoms or concerns. Despite the challenges to building trust and developing relationship, most midwives

felt valued by their clients, and felt they were seen as primary care providers for early pregnancy complications.

## 6.4.2 Feeling valued and recognized within inter-professional relationships

Midwives noted that their interactions with other care providers had an impact on how valued they felt by them. A few midwives felt they had excellent working relationships with nurses and physicians when providing early pregnancy loss care. For example, midwives talked about collegial referrals and smooth transfers of care to physicians. A smaller number of midwives discussed the collaborative sharing of care between providers. For example, Petra discussed how she frequently followed and supported clients after they receive medical treatment from a physician. Marie had similar experiences in her community, where some of the early pregnancy loss care she provided was offered at clients' homes:

I think a big reason why we're able to provide that is our obstetric team, [at] our consulting hospital, has a comfort level with our care...We were doing miscarriage care and calling them, and repeatedly doing that, so from their perspective, it is part of our care provision.

Not all midwives felt as valued or respected by other care providers. In addition to the push-back midwives experienced in relation to their scope of practice, as discussed above, midwives shared several experiences in which their authority and experience was undermined, or where they were excluded from providing care for clients. Morgan shared a story about consulting a physician for a client with a confirmed missed miscarriage. After conducting rounds of lab tests and ultrasounds over several weeks and presenting management options to the client, Morgan referred the client to a local clinic for medical management. The physician responded by questioning Morgan on why she was sending the client there, and by challenging Morgan on why

she was sending a management plan. The physician went on to state that if Morgan was making management plans, then she should be the one to prescribe the medication. Morgan explained her scope of practice to the physician and her rationale behind the management plan, but according to Morgan the physician "just wasn't convinced". The consulting physician then "talked the client into going for another round of [bloodwork] and another ultrasound", which Morgan felt gave the client "false hope" and, ultimately, resulted in her having to "break the client's heart again". Morgan's story not only showed how the lack of value of midwives' skills and abilities has implications on midwives' feelings about providing early pregnancy loss care, but also on the quality of care received by clients.

Roxanne reported feeling encouraged by the changes she has seen in her interprofessional relationships over her 20 years of practice. She relayed a story of a midwife who was not allowed to support an early pregnancy loss client in the emergency department in a hospital where that midwife had privileges. Now, over a decade later, Roxanne feels this would not happen anymore in her community. Despite changes over time, the interview data suggested midwives often needed to prove themselves as competent and skilled providers to other health care professionals in their communities.

## 6.4.3 Being valued within a system: The role of funding and compensation

The sense of being valued extended beyond interactions with clients and other providers to how midwives feel their care they provide is valued and recognized within the broader healthcare system. *All* the midwives interviewed discussed their concerns about their funding models and compensation for early pregnancy loss care. A few midwives noted that funding and compensation was presently on their mind due to an ongoing court case with the provincial government, at the Human Rights Tribunal of Ontario (HRTO), related to pay equity.<sup>115</sup>

Most midwives felt that the current funding model, which compensates them for completing 'courses of care' (12 weeks of care or attending the birth), did not capture the extensive work provided over the course of an early loss. In this sense, both care they provide and the work that they do as providers were perceived as being devalued. "It can be quite a bit of work", reflected Hannah in talking about both the direct client care as well as the bureaucratic aspects of referring or navigating the healthcare system on clients' behalf. Reflecting on a month in which she lost several clients who had early losses, Harriet talked about the time spent on the intake of clients and the accompanying paperwork that was then repeated, without compensation, to replace the lost clients. Further pondering about the implications of the funding model and compensation on midwifery practice, Beatrice said:

I don't know if there's something about our funding model...that somehow makes it feel like [early pregnancy loss care] is a little less important than the other care that we provide...I feel like there is a little bit of a sense of "Oh, okay, you're not going to be a client anymore. Let me wrap up what I need to...and get you on your way". That sounds really callous [but] that's just one thing I've wondered about, is whether some of the way that I was taught to provide early pregnancy care was in the spirit of this isn't really part of the care that we provide.

Thus, for Beatrice's, what midwives do and see as part of their role is somewhat linked with their funding. The funding model thus has implications on how midwives chose to practice. Roxanne, whose practice intentionally enrols clients early in pregnancy, commented that the reason some practices do not take clients until later is not just because of the workload, but "because they don't like having to do the work that will never be compensated for". Some additionally reported seeing midwives quickly wrap-up their care for early pregnancy clients due lack of compensation

for their work. Contemplating on the fact that "there are a lot of midwives in the province who don't want to provide care they are not compensated for", Marie suggested this is not "a bad thing", but rather reflects "a lack of understanding" about the work midwives provide for their clients by those in policy-making positions.

Connecting funding to the earlier discussion about expanding the midwifery scope of practice, several participants felt midwives may be more reluctant to embrace changes to their scope without addressing compensation, as an increased scope of practice would ultimately increase their workload and responsibility. Some midwives felt asking more of them without addressing funding was part of a historic trend. Beatrice reflected on numerous times during her career that tasks "just get added on" to her workload. She further noted:

Because we are not fee-for-service [or] paid an hourly wage, there's no way to capture what that extra workload looks like. So, I think it becomes a bit of a dangerous slope to go down where midwives end up becoming a big cost-savings on the healthcare system, which is great, but kind-of at the expense of themselves.

Additionally, midwives suggested that their compensation model and feeling undervalued has implications on how midwives feel about providing early pregnancy loss care. For some midwives, this care was seen as an "extra piece of care" they provide outside the funding model. Several midwives noted that they often feel like volunteers when providing this care. Harriet further described feeling external pressure as a midwife to go above and beyond the provincial standard of care. Citing the Human Rights Tribunal of Ontario's decision<sup>115</sup> that midwives are under-valued and under-paid, she connects the expectations on midwives for high-quality early pregnancy loss care with expectations related to gender roles, saying "Just because I'm a woman, I'm supposed to be compassionate, and provide this extra care, and [go] above and beyond". As

most midwives in Ontario identify as women, Harriet raised an important point related to the role gender plays in valuing women's health concerns but also the female dominated profession of midwifery. Thus, while most of the midwives within this study were compelled to continue to offer quality early pregnancy loss care for their clients and identified the importance of this work, the importance of feeling valued and recognized cannot be underestimated.

In summary, there is variation among midwives in both the amount and types of early pregnancy loss care they provide. My finding show that midwives are highly responsive to the needs of their communities and clients, as they fill care gaps and provide individualized care to their clients. Midwives see early pregnancy loss care as an important part of the care they provide but are constrained at times by their scope of practice, funding model, and local healthcare resources and providers available, having implications on how they provide care. How midwives feel about providing this care appeared to be tempered by their confidence, their ability to derive satisfaction and meaning from their work, but also by feeling valued and recognized as providers of early pregnancy loss care. My findings further suggest that midwives' experiences of providing care cannot be taken out of the broader healthcare system context in which they work.

# **Chapter 7: Discussion, Contributions, Limitations and Conclusions**

#### 7.1 Discussion

The primary goals of this study were to explore the experiences of midwifery clients accessing and receiving healthcare for early pregnancy loss and to identify how their experiences can be improved. Additionally, I sought to understand the experiences of midwives providing early pregnancy loss care for their clients. I found that two different but complementary types of client experiences emerged from the data: those pertaining to their healthcare journey, which described how clients experienced navigating services or providers for early pregnancy loss, and those pertaining to their interactions with care providers. This finding closely aligns with that of Doyle et al <sup>29</sup> who described the "practical" and "relational" aspects of patient experiences. I additionally found, within both types of experiences that what clients felt, said, and thought about their journey and interactions were an important part of what made up their experiences, as was noted in the literature. <sup>30,31</sup>

The healthcare journey maps depicting the Ontario healthcare context for early pregnancy loss care highlight the considerable variation in how care is delivered, how care overlaps between providers and services, and what pathways clients follow to access and receive care. Coupled with finding that clients were concerned about wait times, continuity of providers, and the challenges related to navigating this complex system, my overall findings suggest that clients navigate their early pregnancy loss care in an uncoordinated and fragmented system, which may result in reduced healthcare quality and efficiency. As my analysis additionally highlights that midwifery care is both a dependent and inter-connected model of care within this healthcare context, improving care for midwifery clients must consider the broader systems context. Thus, I recommend that interventions to improve clients' experiences of care for early pregnancy loss

should aim to streamline and simplify care trajectories, by improving coordination between services and providers, <sup>116</sup> by improving continuity of care from providers, and by improving the navigational support available to clients.

In the exploration of the experiences of midwifery clients, I additionally found that clients' experiences, positive or negative, were largely related to whether their expectations regarding early pregnancy loss care were met. While clients' expectations of their midwifery care appeared to be influenced by how they viewed their loss, as noted in the literature, <sup>37</sup> these expectations also appeared influenced by clients' level of knowledge and confidence surrounding early pregnancy loss and midwifery care. Four inter-connected themes emerged from the data, highlighting the aspects of midwifery care that made the largest difference on client experiences - those being related to access to care, the follow-through by midwives, compassionate care, and receiving information.

The need and desire for information at various points through clients' care emerged as a particularly important aspect of care. Contrary to the findings within the literature that suggested women do not receive adequate information from their care providers,(18) most clients felt well-informed by their midwives. Despite this finding, clients identified a few significant knowledge and information gaps. First, several clients identified the need for more information surrounding the possibility of missed miscarriage. While the best timing of these discussion was not specified, most clients felt midwives could play a role in preparing them for the possibility of early miscarriage. Additionally, several participants identified that they would have appreciated "real" and detailed information about what to expect in terms of symptoms, what they will see, and how they should attend to any remains. Thus, while midwives in general accel at providing information, addressing this information gaps and tailoring information to clients' needs is

important. Also, as most participants sought additional information online, midwives can play a role in directing clients to reputable online resources for further information and support.

The greatest variation in client experiences was related to the follow-through by midwives during their early pregnancy loss care. While several clients felt supported and followed by their midwives, others felt they were dropped by their midwives at varying points during the early pregnancy loss care. Interestingly, the timing of when clients felt dropped often coincided with transitions between the care milestones identified within their healthcare journeys, something that has been described in the literature. 116 Clients' sentiment of feeling dropped is concerning for several reasons. First, most clients accessed healthcare services for early pregnancy loss, showing a desire for healthcare during this time. Additionally, most clients saw midwives as their preferred primary care provider for their whole pregnancy, including for their pregnancy loss. Furthermore, navigating early pregnancy loss care can be overwhelming and difficult within a complex system. More concerningly, I found that those who felt dropped by their midwives had greater difficulty coping, were upset about their care, and were more likely to seek out other care options for their early pregnancy loss and in future pregnancies. As continuity of care is emphasized within the midwifery care model, attention should be given to how midwives can improve their follow-through and navigational support for early pregnancy loss clients who want or need that.

Overall, while the healthcare needs and expectations of participants varied, clients' experiences were more positive when they received individualized and compassionate support from their midwives that helped them understand what to expect and what to do. Thus, clients not only saw midwives as their primary care providers, but also as educators and supportive guides within a complex healthcare system.

While having two data sets added complexity to the analysis, I found understanding the experiences of midwives providing early pregnancy loss care helped situate midwifery client experiences within a broader healthcare context. What constitutes provider experiences has not been described within the literature to the extent that patient experiences have, but I found that midwives described a range of experiences that included their direct interactions with clients, their experiences with other providers, and their subjective feelings about their experiences.

Thus, through a thematic analysis of the data derived from the interviews with midwives, I identified four salient themes that appeared to make the biggest difference in their experiences of providing early pregnancy loss care. Furthermore, I found examining these themes offers further insight on why there was so much variation in midwifery care for early pregnancy loss, and why within a client-centred model some clients felt their expectations are not met.

I found that the midwives interviewed see early pregnancy loss care as an important part of their work, and that many derived a sense of satisfaction from providing this care. Midwives largely described providing care within client-centred care model that includes pager access and providing out-of-hospital care, but also tailoring information and care to individuals and community needs. However, midwives were at times challenged in their ability to provide the care they wanted due to external forces related to how they are organized, regulated, and compensated. For example, within their practice groups, both, heavy workloads and practice culture informed whether they take clients into care early or prioritize the care for clients experiencing early pregnancy loss. Additionally, several midwives identified feeling constrained in their ability to meet clients' care needs by what local resources available, but more importantly by the regulation related to their scope of practice. More importantly, my findings suggest midwives face ongoing challenges related to the integration of their client-centred care

model within the broader healthcare system, a finding that is not new within the literature. 117,118

For example, midwives discussed going against the grain and experiencing push-back from other health care providers while offering early pregnancy loss care. These findings suggest a possible collision between differing care models and philosophies, but also that of long-standing interprofessional turf issues and power relationships. My findings also suggest that midwives overwhelmingly felt the work they put into providing early pregnancy loss care is largely undervalued. This finding may be one of the most important factors contributing to the variation in how midwives provide early pregnancy loss care across the province, but also how they feel about it. Thus, overall, midwives' experiences of providing care are largely impacted by their professional status and integration within the healthcare system, which has implications for the care provided to clients.

As the experiences of midwives and their clients are interconnected, determining how to improve the experiences of providing early pregnancy loss care for midwives is an important consideration for improving the care quality for their clients. An increased interest in the adoption of a Quadruple Aim of health systems that includes the aim of improving provider experiences supports this finding. Indeed, improving provider experiences has been connected with increased job satisfaction and reduced burnout, the latter a concern often discussed within the midwifery literature. While there is little academic literature to describe how to more broadly improve provider experiences, grey literature on the topic suggests that consideration needs to be given to improving providers' ability to do their job but also their ability to derive meaning from their work, which closely aligned with my findings.

Based on my findings, improving midwives' ability to provide early pregnancy loss care will require a systems approach. First, there was a general consensus among midwives that

increasing the midwifery scope of practice to include the prescribing of misoprostol would increase their ability to follow clients and streamline care, fill healthcare gaps in some communities, and reduce strain on the healthcare system. This study thus offers evidence to support the upcoming changes to the midwifery pharmacopeia to include misoprostol. Additionally, as several midwives cited concerns about the payment for early pregnancy loss care, I recommend that further evaluation of how Expanded Midwifery Care Models (EMCMs) can help create innovative solutions for the compensation of early pregnancy loss care is needed, but caution that this model should not be seen as a solution for those working within the courseof-care compensation model. I further recommend that policy makers consider how to ensure midwives feel valued and recognized as providers of early pregnancy loss care, particularly if their scope of practice and thus responsibility are to increase. Furthermore, most midwife participants identified that how equipped they felt to provide early pregnancy loss care had implications on how and to what extent they provide care. Offering opportunities to increase early pregnancy loss care knowledge among midwives, thus increasing their confidence in their ability to provide this type of care, can be administered through initial training and subsequent educational opportunities. Having access to training modules and clinical practice guidelines on the management of early pregnancy loss would also be an asset.

While I found that midwives experiences were tempered by whether they derived as sense of satisfaction or meaning from providing early pregnancy loss care, finding a way to increase a providers' sense of meaning and satisfaction from their work is a complex task. My findings suggest that not every midwife is currently interested in or positioned to offer more early pregnancy loss care, nor is the care needed to the same extent in every community. Thus, I

suggest that midwives should be supported in tailoring the early pregnancy loss care they provide to the needs of their communities.

Within the complexity of the maternal healthcare context for early pregnancy loss, important insights have been gained from analyzing the experiences of both clients and midwives, highlighting the importance of centering, understanding and improving these experiences when attempting to improve the quality of care. Additionally, applying a systems lens highlighted how these experiences are not only interconnected, but are also impacted by healthcare organizations, policies, and regulations, further helping to identify points of intervention. Furthermore, while midwifery is among several overlapping providers and services for early pregnancy loss, my findings suggest the midwifery model of care offers unique aspects of care that are valued by midwifery clients. Instead of concerns that midwives are weakening the health system by being a duplicate service, I suggest they add resilience to the healthcare system by keeping clients home with timely access to skilled care and reducing the need for emergency or specialist care. <sup>99</sup> This is an important offering when other parts of the healthcare system are weakened or have other priorities, such as in the context of Covid-19.

## 7.2 Research and Theoretical Contributions

By applying both critical feminist and systems theoretical lenses, this study can offer some insights on how they intersect, a unique theoretical perspective that has had limited examination to date. 104 Ultimately, using both lenses helped identify dominant discourses that inform and influence the priorities and policies within a system, which, in turn, impact the experiences of patients and providers. Like other studies, my findings identified a dominant discourse that supports a culture of silence that exists around early pregnancy loss, 11,12,22,37 but also favours fertility and motherhood. 124 What my findings further contribute is an

acknowledgement that these discourses have influenced the priorities of healthcare systems. For clients, the implications are seen in their lack of knowledge about early pregnancy loss, the lack of information available, and in their experiences of fertility stigma and shaming. For midwives, the culture of silence around early pregnancy loss has had implications on their training and knowledge, and their funding models which emphasize and value the care for ongoing pregnancies and births. The resulting fragmented healthcare system in which women so often seek early pregnancy loss care in ED or need to navigate receiving care on their own, further reflect the implications of culture on setting healthcare system priorities. Thus, to improve the care received for early pregnancy loss, changes to the culture that informs our healthcare system are needed to break the silence around this healthcare concern and its impact. Additionally, applying a combined theoretical approach has highlighted traditional power structures within the healthcare system that favour the medicalization of early pregnancy loss and challenge the integration of midwifery skill and knowledge. Thus, given the potential usefulness in exploring gendered experiences within a systems context, I suggest that further exploration of how these theories intersect is warranted.

This study also contributed new findings to the growing body of literature addressing women's experiences receiving healthcare for early pregnancy loss as the first midwifery-specific study addressing client experiences of accessing and receiving care for early pregnancy loss. While this study adds to the growing consensus that healthcare for early pregnancy loss can and should be improved,<sup>18</sup> it also highlights the ways in which the midwifery model of care is both ideal and constrained in its ability to provide early pregnancy loss care. Additionally, this study is among a small number of studies that incorporated the experiences of providers. <sup>2,11,35,66</sup> Including provider experiences offer more depth and understanding on how, at a systems level,

to improve the quality of care for clients. Further research is clearly needed on both what constitutes provider experiences and how they can also be improved.

#### 7.3 Limitations and Considerations

My study had some limitations. First, as this was a small exploratory study, the number of participants may be a limitation to the generalizability of the results. The exploratory design of this study and thematic analytic approach somewhat mitigate the small participant size by giving room for the range of experiences that emerged from the rich data. Additionally, this study will be situated among qualitative studies with comparable, if not smaller sample sizes. 11,12,23 Related to sample size, it was both a strength and limitation to include participants who had not started their midwifery care in early pregnancy. While their involvement highlighted issues related to access and navigating care from other providers and services, the number of participants actually utilizing midwifery care was reduced. The sample size also impacted the diversity of participants and their experiences within the sample. While recruitment was brisk, goals on sample size met, and the study received over-whelming positive feedback from participants, the client participants had a lot in common. As all client participants were highly educated, identified as female, and all but three identified as white, findings of this study should be considered with the social agency and privilege of the participants in mind. Despite the commonalities among participants, the interviews generated rich data and a diverse set of experiences. Several participants, noting their privilege, considered how, if the experience was difficult for them, it would feel for someone with less agency, education, or means to seek and navigate early pregnancy loss care. Future research on this topic needs to make greater attempts to centre voices from marginalized communities and the midwives who serve them.

The use of healthcare journeys as an analytic tool to explore client data was additionally accompanied by some limitations, despite it being an interesting approach. First, while I encountered several studies that have utilized healthcare journey mapping, 23,31,111 there was no consensus or guidelines on how to proceed. Seeing the lack of guidance as endorsement for both flexibility and for iteratively adapting this analytic tool to the data available, I took a rather simplified approach that emphasized points of access and interaction with providers and services through four main care milestones. A second challenge was related to the accuracy of the healthcare journeys. As the healthcare journeys were devised from the interview data, there were sometimes obvious gaps in the information available. Additionally, interview data often captures how participants' experiences are interpreted and remembered. 94 As this study tended to see the interview data through a more critical lens, the healthcare journeys should be interpreted as guides on what clients felt was important within the interview data. To strengthen the utility, accuracy and findings of healthcare journeys, researchers may consider either having participants generate their own healthcare journey maps prior to the interviews or have them review their journeys after as a means of verification. 112

Lastly, as the use of semi-structured interviews, by their nature, engage with participants where they are at, and attempt to elicit participants' understanding of their experiences, 94 there are further challenges when using and analyzing interview data. First, the interview space is not seen as benign and has been described as a "liminal space" where researcher and participants both bring prior knowledge and experiences, which contribute to knowledge building. 125 Second, challenges arise when using interview data, as the experiences remembered and interpreted may no reflect what is happening in healthcare contexts. 94 Alternate methodological approaches may have offered a means to strengthen the findings. For example, institutional ethnography embeds

the researcher within an institutional context and utilizes observational methods of work environments, social interactions, and behaviours.<sup>126</sup> While observations within healthcare settings were beyond the scope of this study, and may have been difficult for the care of early pregnancy loss, further research may be warranted on the healthcare spaces in which midwives provide care,<sup>127</sup> including that of the home, which emerged as an important setting of healthcare within my data.

## 7.4 Conclusions

This study sought to understand the experiences of midwifery clients receiving care for early pregnancy loss, as well as the experiences of midwives providing care. Client experiences encompassed those relating to their healthcare journey, and those relating to their interactions with their care providers, as well as what they thought and felt about their experiences of accessing and receiving care. By eliciting participants' experiences within the midwifery model of healthcare for early pregnancy loss, this study highlights how midwifery care is situated as a dependent and interconnected healthcare service within a complex and fragmented maternal healthcare system. While not all clients had the same healthcare needs or expectations when early pregnancy loss occurs, the experiences of midwifery clients were improved when they received individualized, compassionate guidance and support, and adequate information to know what to expect and do. Challenges faced by midwives related to their work context, organization, regulation and payment had implications on both their ability to provide care and how they felt about providing it. Thus, interventions to improve client care should look beyond client-provider interactions and consider ways to improve midwives' experiences and their ability to meet their client needs. Furthermore, to improve women's experiences, a more coordinated, patientcentered response at a systems level is needed. This is the first study to examine the midwifery

model of care for early pregnancy loss care from the perspectives of clients and midwives. Thus, this study contributes valuable insights to the scholarship on women's experiences of healthcare for early pregnancy loss, as well as on the experiences of providers within a broader healthcare context. Findings from this study contribute to recommendations for practice, policy, and research with the goal to improve the healthcare quality for those with early pregnancy loss.

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#### **Appendices**

#### **Appendix A – Recruitment Email Script**

Dear all,

This email is being sent on behalf graduate student researcher, Angela Freeman, RM.

I am currently working on a research study for my master's thesis at the University of Waterloo entitled: *Navigating Early Pregnancy Loss Within Ontario's Healthcare System: A qualitative exploratory study of midwives and their clients*. My graduate thesis supervisor is Dr. Elena Neiterman.

The purpose of this study is to explore how the maternity healthcare system and specifically the midwifery model of care is experienced from both the perspectives of midwives and their clients in cases of early pregnancy loss (<14 wks. gestation). This study will explore how midwifery clients, and those wanting midwifery care, navigate, access and experience their care in cases of early miscarriage. Additionally, this study will explore the experiences of providing early pregnancy loss care within the current midwifery model in Ontario. Findings from this study may inform clinical practice and policy with the goal to improve access and quality of care for patients and providers in early pregnancy.

I am currently looking for volunteers to take part in interviews and share their healthcare experiences. For purposes of this study I am seeking participants who meet the following criteria:

- 1. Midwives practicing in Ontario, working in any model or funding arrangement, who have greater than one year of clinical experience.
- 2. Individuals (18-45 yrs.) who have experienced a first trimester loss (<13 wks.) within the past 3 years, and considered, requested or used midwifery care in any capacity.

Your participation will remain confidential.

I have attached a Letter of Information and Consent Form where you can learn more about the study and its procedures. Please consider sharing with your contacts who you think may be interested in participating.

Please feel free to contact me regarding participation or any questions you may have at <a href="mailto:ar2freeman@uwaterloo.ca">ar2freeman@uwaterloo.ca</a> or by text/phone at <a href="mailto:ar2freeman@uwaterloo.ca">ar2freeman@uwaterloo.ca</a> or arafreeman@uwaterloo.ca</a>

Sincerely,

Angela Freeman, RM MSc Candidate School of Public Health and Health Systems Faculty of Applied Health Sciences University of Waterloo

> This study has been reviewed by and received ethics clearance through a University of Waterloo Research Ethics Committee.

#### **Appendix B – Recruitment Poster for Clients**



**FACULTY OF APPLIED HEALTH SCIENCES** | School of Public Health and Health Systems 519-888-4567 | fax 519-746-6776 uwaterloo.ca/public-health-and-health-systems

# RESEARCH PARTICIPANTS NEEDED for study entitled

Navigating early pregnancy loss within Ontario's healthcare system: A qualitative exploratory study of midwives and their clients

If you are between the ages of 18-45, had an early pregnancy loss (less than 13 wks. pregnant) within the last three years, and considered, requested or used midwifery care in any capacity, we would like to hear about your experiences.

As a participant in this study, you will be asked to take part in an open-ended interview, for approximately 40-60 minutes. The questions will focus on how you made healthcare decisions, the role of midwives in your overall healthcare experience, and how your felt about the healthcare you received during and after your miscarriage.

This research will not benefit you directly, but we hope to learn more about how midwifery care fits within the Ontario healthcare system for miscarriage, and how services can improve to support those experiencing early pregnancy loss.

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

# Angela Freeman, Registered Midwife Master of Science Candidate

Phone:

Email: ar2freeman@uwaterloo.ca

This study has been reviewed by Dr. Elena Neiterman, and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#41475).

#### **Appendix C – Recruitment Poster for Midwives**



**FACULTY OF APPLIED HEALTH SCIENCES** | School of Public Health and Health Systems 519-888-4567 | fax 519-746-6776 uwaterloo.ca/public-health-and-health-systems

# RESEARCH PARTICIPANTS NEEDED

for study entitled

# Navigating early pregnancy loss within Ontario's healthcare system: A qualitative exploratory study of midwives and their clients

We are looking for midwife volunteers to take part in a study that explores the roles midwives play or could play in providing care to their clients in cases of early miscarriage.

If you are a midwife practicing in Ontario, with over a year of clinical experience, we would like to hear from you.

As a participant in this study, you will be asked to take part in an open-ended interview, for approximately 20-30 minutes. The questions will focus on the care you offer to clients in cases of early pregnancy loss (<13 wks. gestation), how you see midwifery fitting within the larger healthcare context, as well as barriers and opportunities within the midwifery model for miscarriage care.

By conducting this study we hope to learn more about the midwifery model of care for early miscarriage, how this model is experienced by those providing and using midwifery care, how it fits within the larger maternity care system and how services can improve to support those experiencing early pregnancy loss.

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

Angela Freeman, RM Master of Science Candidate

Phone:

Email: ar2freeman@uwaterloo.ca

This study has been reviewed by Dr. Elena Neiterman and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#41475).

#### Appendix D – Newsletter Post for AOM 'Midwifery Memo'

Midwife and client participants needed for a study entitled: Navigating early pregnancy loss within Ontario's healthcare system: A qualitative exploratory study of midwives and their clients. The purpose of this study is to explore the experiences of both midwives and their clients in providing and receiving healthcare for early miscarriage (less than 13 weeks gestation) in the Ontario context. Participants will be asked to take part in a confidential interview lasting approximately 30 minutes. The data collected during the interviews will contribute to a better understanding of the midwifery model of care for early miscarriage, how this model is experienced by those providing and using midwifery care, and how it fits within the larger maternity care system context. This research is being conducted as part of a master's thesis at the University of Waterloo and has received ethics clearance.

For more information about the study or participation please contact student researcher, Angela Freeman, RM, at: ar2freeman@uwaterloo.ca or , or <LinkedIn profile>.

#### Appendix E – Letter of Information (LOI) and Consent - Clients



**FACULTY OF APPLIED HEALTH SCIENCES** | School of Public Health and Health Systems 519-888-4567 | fax 519-746-6776 uwaterloo.ca/public-health-and-health-systems

**Study Title:** Navigating early pregnancy loss within Ontario's healthcare system: A qualitative exploratory study of midwives and their clients

**Faculty Supervisor:** Elena Neiterman, PhD, School of Public Health and Health Systems, University of Waterloo. Phone: (519) 888-4567 ext. 38221, Email: eneiterman@uwaterloo.ca

**Student Investigator:** Angela Freeman, RM, MSc Candidate, School of Public Health and Health Systems, University of Waterloo. Phone: (519) Email: <a href="mailto:ar2freeman@uwaterloo.ca">ar2freeman@uwaterloo.ca</a>

Dear Potential Participant,

To help you make an informed decision regarding your participation, this letter will explain what this study is about, the possible risks and benefits, and your rights as a research participant. If you do not understand something in the letter, please ask Angela Freeman prior to consenting to the study. You will be provided with a copy of the information and consent form if you choose to participate in the study.

#### **Invitation to Participation and Study Description:**

You are invited to participate in a study being conducted by Angela Freeman, RM, as part of her Master's thesis research through the University of Waterloo. The purpose of this study is to explore the experiences of both midwives and their clients in providing and receiving healthcare for early miscarriage (less than 13 wks. gestation) in the Ontario context. The goals of this research are to increase our understanding of the midwifery model of care for early miscarriage, how this model is experienced by those providing and using midwifery care, and how it fits within the larger maternity care system context. The ultimate goal of this study is to offer insights on how to improve healthcare experiences for healthcare users and providers.

#### I. Your Responsibilities as a Participant:

#### What does participation involve?

If you decide to volunteer, you will be asked to take part in an individual interview that will take approximately 40-60 minutes to complete. The interview will be scheduled at a location, date and time that is convenient for you. The interview may take place in-person, or by phone or Skype\*, depending on your preference and geographical location.

At the time of the interview you will be assigned a participant code to anonymize any information you share. You will first be asked to answer a few demographic questions (i.e., Age, gender, education). These questions will not be audio-recorded and will not be attached to your name. Once the interview starts, you will be asked open-ended questions that will focus on your healthcare experiences, including that of your midwifery care, during an early miscarriage (within the first trimester). In general, you will be asked questions about how you made decisions about your healthcare (such as information or supports you used), what are the healthcare services you used, what role your midwife played within your care, and what suggestions you have on how your care experience could have been improved.

\*For Skype interviews: When information is transmitted ower the intercept privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies,

hackers). University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device without first informing you. If you prefer not to participate using this online method, please let the researcher know so you can participate using an alternative method such a telephone call/in-person.

The interview will be audio recorded to ensure an accurate transcript. With your permission, anonymous quotations may be used in publications and/or presentations.

#### Who may participate in this study?

In order to participate you must be between 18-45 years old and be able to speak and understand English. Additionally, you must meet the following criteria to be eligible to participate:

- Personally experienced an early pregnancy loss (less than 13 weeks pregnant)
- The length of time since your miscarriage should be between 1 month and 3 years
- You must have considered, requested or used midwifery care in any capacity as part of your pregnancy or miscarriage care.

#### II. Your Rights as a Participant:

#### Is this study voluntary?

Your participation in this study is completely voluntary. You may decide to leave the study at any time prior to or during the interview by communicating your request to the researcher. Within the interview you may decline to answer any question(s) you prefer not to answer by requesting to skip a question. Following the interview session, you may completely withdraw from the study up to two weeks following your interview by contacting the researchers.

#### Will I receive anything for participating in this study?

You will not receive payment for your participation in this study.

#### What are the possible benefits of this study?

Participation in this study may not provide any personal benefit to you, but the knowledge gained from this study may be used to inform policy or make healthcare system recommendations on how to improve the provision of early miscarriage care in Ontario.

#### Are there any risks to participating?

The risks of participating in this study are considered minimal, but if you have experienced an early pregnancy loss you may find talking about your healthcare experiences during that time difficult. You may for example experience emotional upset, sadness, and some questions may bring up memories that are distressing to you. We will attempt to minimize the risk by moving at your pace through the interview and by using your preferred language to describe your experience. Importantly, you may decline to answer any of the interview questions if you so wish, and the interview can be paused or discontinued at any point. Resources will be made available, if wanted, to support you after your participation.

#### i. Will my personal information remain confidential? Will I be identifiable?

Your confidentiality is very important throughout this research project.

With your permission, we will gather some of your demographic information, such as your age, gender, geographic setting of dwelling (rural, urban), number of pregnancies and losses, and number of weeks gestation of your miscarriage. To ensure the confidentiality of your data, you will be identified by a participant code and a pseudonym of your choice. Any publications or reports that result from this study

will present the demographic information as grouped data (i.e., numbers or averages of all the participants).

With your permission, the interview will be audio-recorded to facilitate the accurate collection of information, and later transcribed for analysis. Within this audio-recording, your name will not be used, but your voice may be heard. The audio recording collected during this study will be destroyed immediately upon transcription (within two weeks of the interview) and only the anonymized transcript from the interview will be retained. All information that could identify you will be deleted from the interview transcript. Only the research team will know which data is from your participation, and any identifying information will be kept separate from the data.

Only researchers associated with this study will have access to any study records. Your interview transcript will be stored under an anonymous participant code, encrypted and stored on a password-protected computer that is only available to the researcher. Encryption of electronic files will be conducted according to University of Waterloo IST policy. Any paper data, such as consent forms or demographic information, will be stored in a secure location. We will keep your data for the period seven years following the date of the interview, after which it will be destroyed according to University of Waterloo policy.

#### ii. Are there risks to my confidentiality?

The primary researcher is a non-practicing midwife who will solely be in the role of investigator, not clinician, during the research process. As a midwife, the researcher has a legal duty to report any form of child abuse reported or evident during the interview process, which would affect the protection of your confidentiality.

#### **III.** Questions, Comments, Concerns

#### i. How is this study funded?

This study has not received any funding and there are no conflicts of interest to declare.

#### ii. Has the study received ethics clearance?

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#41475). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or at ore-ceo@uwaterloo.ca

#### iii. Who should I contact if I have questions about my participation in the study?

For all other questions regarding this study, or if you would like additional information to assist you in reaching a decision about participation, please contact me by email at <a href="mailto:ar2freeman@uwaterloo.ca">ar2freeman@uwaterloo.ca</a>. You can also contact my supervisor, Dr. Elena Neiterman, at (519) 888-4567 ext. 38221 or email eneiterman@uwaterloo.ca

Yours Sincerely,

Angela Freeman, RM, MSc Candidate

#### **CONSENT FORM**

I have read the information presented in the information letter about a study being conducted by Angela Freeman, under the supervision of Dr. Elena Neiterman. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the findings of this study with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time during the interview by advising the investigator, and up to two weeks following the interview by contacting the researchers.

This study has been reviewed and received ethics clearance through a University of Waterloo Research

Research Ethics, at 1-519-888-4567 ext. 36005 or	that it I have any questions, I may contact Office of ore-ceo@uwaterloo.ca.
With full knowledge of all foregoing, I agree, of r  YES NO	my own free will, to participate in this study.
I agree to have my interview audio recorded.  YES NO	
I agree to the use of anonymous quotations in future project.  YES NO	are research projects/publications developed from this
I give permission to Angela Freeman to retain the use it for research purposes as long as it has no id YES NO	transcript from my interview for up to 5 years and to entifiable information that ties it to me
By signing this consent form, you are not waiving involved institution(s) from their legal and profess	g your legal rights or releasing the investigator(s) or sional responsibilities.
Participant Name:	(Please print)
Participant Signature:	
Witness Name:	(Please print)
Witness Signature:	
Data	

#### Appendix F- Letter of Information (LOI) and Consent – Midwives



**FACULTY OF APPLIED HEALTH SCIENCES** | School of Public Health and Health Systems 519-888-4567 | fax 519-746-6776 uwaterloo.ca/public-health-and-health-systems

**Study Title:** Navigating early pregnancy loss within Ontario's healthcare system: A qualitative exploratory study of midwives and their clients

**Faculty Supervisor:** Elena Neiterman, PhD, School of Public Health and Health Systems, University of Waterloo. Phone: (519) 888-4567 ext. 38221, Email: eneiterman@uwaterloo.ca

**Student Investigator:** Angela Freeman, RM, MSc Candidate, School of Public Health and Health Systems, University of Waterloo. Phone: Email: <a href="mailto:ar2freeman@uwaterloo.ca">ar2freeman@uwaterloo.ca</a>

Dear Potential Participant,

To help you make an informed decision regarding your participation, this letter will explain what this study is about, the possible risks and benefits, and your rights as a research participant. If you do not understand something in the letter, please ask Angela Freeman prior to consenting to the study. You will be provided with a copy of the information and consent form if you choose to participate in the study.

#### **Invitation to Participation and Study Description:**

You are invited to participate in a study being conducted by Angela Freeman, RM, as part of her Master's thesis research through the University of Waterloo. The purpose of this study is to explore the experiences of both midwives and their clients in providing and receiving healthcare for early miscarriage (less than 14 weeks gestation) in the Ontario context. The goals of this research are to increase our understanding of the midwifery model of care for early miscarriage, how this model is experienced by those providing and using midwifery care, and how it fits within the larger maternity care system context. The ultimate goal of this study is to offer insights on how to improve healthcare experiences for healthcare users and providers.

#### IV. Your Responsibilities as a Participant:

#### What does participation involve?

If you decide to volunteer, and meet the eligibility criteria, you will be asked to take part in an individual interview that will take approximately 20-30 minutes to complete. The interview will be scheduled at a location, date and time that is convenient for you. The interview may take place in-person, or by phone or Skype\*, depending on your preference and geographical location.

At the time of the interview you will be assigned a participant code and asked your preferred pseudonym to anonymize any information you share. Once the interview starts, you will be asked open-ended questions that will focus on your experiences providing early miscarriage care to your clients within the Ontario healthcare context. For example, you will be asked questions about the midwifery model of care for miscarriage, the care or services you provide your clients, how you see yourself as a midwife fitting within the broader maternity care system, and any barriers you can identify to providing early miscarriage care. \*For Skype interviews: When information is transmitted over the internet privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies, hackers). University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device without first informing you. If you prefer not to participate using this ending method, please let the 3G1 researcher know so you can participate using an alternative method such a telephone call/in-person.

The interview will be audio recorded to ensure an accurate transcript. With your permission, anonymous quotations may be used in publications and/or presentations.

#### Who may participate in this study?

In order to participate you must be 18 years old or older, and able to speak and understand English. Additionally, to participate in this study, you must be a practicing midwife in Ontario with at least one year of professional experience.

#### V. Your Rights as a Participant:

#### Is this study voluntary?

Your participation in this study is completely voluntary. You may decide to leave the study at any time prior to or during the interview by communicating your request to the researcher. Within the interview you may decline to answer any question(s) you prefer not to answer by requesting to skip a question. Following the interview session, you may completely withdraw from the study up to two weeks following your interview by contacting the researchers.

#### Will I receive anything for participating in this study?

You will not receive payment for your participation in this study.

#### What are the possible benefits of this study?

Participation in this study may not provide any personal benefit to you, but the knowledge gained from this study may be used to inform policy or make healthcare system recommendations on how to improve the provision of early miscarriage care in Ontario.

#### Are there any risks to participating?

The risks of participating in this study are considered minimal, but if you have experienced an early pregnancy loss or you have provided care to someone who has had a traumatic early miscarriage experience you may find talking about these experiences difficult. We will attempt to minimize the risk by moving at your pace through the interview. Importantly, you may decline to answer any of the interview questions if you so wish by requesting to pass. Interviews can be paused or discontinued at any point. Resources will be made available, if wanted, as to support you after your participation.

#### Will my personal information remain confidential? Will I be identifiable?

Your confidentiality is very important throughout this research project.

With your permission, we will gather some of your demographic information, such as your age, gender, race/ethnicity. To ensure the confidentiality of your data, you will be identified by a participant code and pseudonym of your choice known only to the researchers. Any publications or reports that result from this study will present the demographic information as grouped data (i.e., numbers or averages of all the participants).

With your permission, the interview will be audio-recorded to facilitate the accurate collection of information, and later transcribed for analysis. Within this audio-recording, your name will not be used, but your voice may be heard. The audio recording collected during this study will be destroyed immediately upon transcription (within one week of the interview) and only the anonymized transcript from the interview will be retained. All information that could identify you will be deleted from the interview transcript. Only the research team will know which data is from your participation, and any identifying information will be kept separate from the data.

Only researchers associated with this study will have access to any study records. Your interview transcript will be stored under an anonymous participant code, encrypted and stored on a password-protected computer that is only available to the researcher. Encryption of electronic files will be conducted according to University of Waterloo IST policy. Any paper data, such as consent forms or demographic information, will be stored in a secure location. We will keep your data for the period seven years following the date of the interview, after which it will be destroyed according to University of Waterloo policy.

#### Are there risks to my confidentiality?

The primary researcher is a non-practicing midwife who will solely be in the role of investigator, not clinician, during the research process. As a midwife, the researcher has a legal duty to report any form of child abuse reported or evident during the interview process, which would affect the protection of your confidentiality should this issue arise.

#### VI. Questions, Comments, Concerns

#### How is this study funded?

This study has not received any funding and there are no conflicts of interest to declare.

#### Has the study received ethics clearance?

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#41475). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or at ore-ceo@uwaterloo.ca

#### Who should I contact if I have questions about my participation in the study?

For all other questions regarding this study, or if you would like additional information to assist you in reaching a decision about participation, please contact me by email at <a href="mailto:ar2freeman@uwaterloo.ca">ar2freeman@uwaterloo.ca</a>. You can also contact my supervisor, Dr. Elena Neiterman, at (519) 888-4567 ext. 38221 or email <a href="mailto:eneiterman@uwaterloo.ca">eneiterman@uwaterloo.ca</a>

Yours Sincerely,

Angela Freeman, RM, MSc Candidate

#### **CONSENT FORM**

I have read the information presented in the information letter about a study being conducted by Angela Freeman, under the supervision of Dr. Elena Neiterman. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the findings of this study with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time during the interview by advising the investigator, and up to two weeks following the interview by contacting the researchers.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#41475). I was informed that if I ha

Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.
With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.
□YES □NO
I agree to have my interview audio recorded.
□YES □NO
I agree to the use of anonymous quotations in future research projects/publications developed from this project.
□YES □NO
I give permission to Angela Freeman to retain the transcript from my interview for up to 7 years and to
use it for research purposes as long as it has no identifiable information that ties it to me.  YES NO
By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or
involved institution(s) from their legal and professional responsibilities.
Participant Name:(Please print)
Participant Signature:
Witness Name: (Please print)
Witness Signature:
Data

# Appendix G – Client Demographic Form

**Study:** Navigating early pregnancy loss within Ontario's healthcare system: A qualitative exploratory study of midwives and their clients.

Client participants will be asked the following questions prior to taking part in an interview.

Participant Code (i.e., C1):
Preferred Pseudonym:
*Age (between 18-45):
Marital or relationship status:
Gender identity:
Race/Ethnicity:
Level of Education:
Can you describe where you live in terms of setting? (urban, semi-urban, rural, remote):
Can you describe where you access healthcare services? (urban, semi-urban, rural, remote):
*Have you personally experienced an early miscarriage? (Y/N):
*How long ago did your loss occur? (> 1 month to <3 years):
*How many weeks pregnant were you at the time of your loss? (<13 wks. gestation):
Number of pregnancies/Are you currently pregnant:
*Are you currently in a state of emotional distress or experiencing severe anxiety or depression related to the pregnancy loss? If yes, participant will not be able to participate in the study, and researcher will suggest services and resources, and any information shared above will be destroyed.
*Confirm desire/intent to use or utilization of midwifery care in Ontario:  under wanted midwives but no midwives locally available  called into care/not accommodated  booked into midwifery care, but not a client yet  had one or more midwifery appointments

#### Appendix H - Interview Guide for Clients

#### **Midwifery Client Interview Guide**

- 1. Can you walk me through your health care journey, including that with your midwife and other health care providers, from the start of your symptoms?
- 2. Can you describe when and how you identified that there may be a concern with your pregnancy?
- 3. Can you tell me how you felt at this time?
  - ➤ How did you feel about the pregnancy?
  - ➤ What emotions did you experience when you started to have symptoms?
- 4. At what point did you decide to seek health care? And where or from whom? (What was your first step?)
  - ➤ How did you come to this decision?
  - > Did anyone help you come to the decision to seek health care services?
  - ➤ Was this your first choice for healthcare services/setting? What healthcare setting is best suited to provide miscarriage care?
  - ➤ What options were you aware of or did you consider?
  - ➤ How did midwifery fit or not into your decision-making?
- 5. What were you expecting or hoping from your health care providers when you accessed care? (i.e., Diagnostic Investigations? Information?)
- 6. How were you cared for during your miscarriage?
  - ➤ Who provided your miscarriage care?
  - ➤ What healthcare services did you use? (i.e., hospital/ED, EPAC, midwives, labs/diagnostics)
  - ➤ What management options were you offered when you? (Were you offered any blood testing or ultrasounds? Were you offered to "wait and see", take a medication or have surgery?)
- 7. How would you describe your knowledge of miscarriage prior to your loss?
  - ➤ What sources of information, if any, did you access about your symptoms or miscarriage? (i.e.. Online, information from care providers)
  - At what points during or after your experience did you access information?
  - ➤ Did the information you sought meet your needs? In what way?
  - ➤ Did you feel informed enough to make decisions about your miscarriage care options?
- 8. Overall, what were your perceptions and experiences of the care you received?
- 9. What was your experience using and accessing your midwife during your miscarriage?
  - > Describe the role your midwife played in your care?

- ➤ How accessible or reachable was your midwife?
- ➤ Did you feel confident in your midwife's skills and abilities?
- > Do you think your experience would have been different if you did not have a midwife?
- 10. Can you describe any follow-up care you were offered or used after your miscarriage (i.e., counselling, primary care provider (RM, RNEC, MD), further tests, phone call or appointment)?
  - ➤ What were your feelings about the care you received after your miscarriage?
  - Are there services you wanted offered or to access that you didn't? What ones?
- 11. What, if anything, would you change or improve in your health care experiences?
  - ➤ Would you say your health care needs were met during your loss? In what ways?

For clients who had previous pregnancies or multiple miscarriage experiences:

- 12. Do you think (being a mother prior to the loss/having prior experience with early pregnancy loss) changed your level of knowledge or understanding of what to expect in your healthcare experience this time? In what way?
  - ➤ Do you feel you had greater knowledge or information?
  - ➤ Did you feel more able to ask questions or ask for what you needed?
  - ➤ Did your previous experience(s) shape your healthcare decisions in any way (ie. what care provider/care setting to use?).
- 13. Is there anything that you would like to add?

#### **Appendix I – Interview Guide for Midwives**

### **Registered Midwife Interview Guide**

- 1. Can you briefly describe your midwifery practice in terms of the model you work in (ie. caseload midwifery (specify primary or shared care), CHC, EMCM), as well as the geographic setting in which you provide care (urban, semi/small urban, mixed, rural, remote)?
  - Is there a particular demographic or community your practice provides care for?
- 2. Please describe for me your experience as a midwife in providing client care in cases of early pregnancy loss (first trimester)?
- 3. How frequently do you provide early pregnancy loss care?
  - Approximately how many early miscarriages do you encounter within a year?
  - At what gestation do clients typically start in your practice?
- 4. Can you briefly describe your midwifery practice clientele? Would you say there is a dominant way of understanding miscarriage or early pregnancy loss by your clients?
- 5. What do you see as your role, as a midwife, in providing early miscarriage care? For clients? Within a healthcare system?
- 6. What do the services and care you provide for early miscarriage typically look like?
  - Are your services in person? By phone?
  - If in person, where do you see your clients?
  - Do you keep or refer care to other health care providers or settings (i.e., the ED/Early Pregnancy Unit/OBs)?
  - What information do you provide your clients when they call with symptoms?
  - What test and screens do you offer your clients presenting with symptoms?
  - What management options do you provide your clients?
- 7. What information, if any, do you provide for your clients in early pregnancy (ie. at booking visits) about the risk of pregnancy loss or miscarriage? Or about related complications?
  - What do you feel your clients should know or understand about miscarriage?
- 8. Following an early miscarriage, is it your practice to follow-up with clients? (visit, phone call)?
- 9. Can you describe, if any, counselling services you offer, recommend, or make referrals to?

- 10. Where else do your clients or women in your community seek healthcare for early pregnancy complications, such as miscarriage?
- 11. How would you describe your relationships with other healthcare providers you may refer to for early pregnancy loss?
- 12. How would you describe your level of knowledge related to early miscarriage as a whole (rate, causes and risk factors, management options, presentation and symptoms, blood loss, emotional aspects)?
- 13. Describe your confidence level in providing miscarriage care?
  - How do you feel your education did/did not prepare you to provide miscarriage care?
  - Do you feel you currently have any gaps in your skill set in providing miscarriage care?
- 14. What sources of information do you most rely on to guide your management in cases of EPL? (i.e., research, clinical practice guidelines, practice protocols, etc)
  - Does your practice have a protocol for early pregnancy loss care?
- 15. Have you taken any courses or additional training to enhance or support your work as an early pregnancy provider? (i.e., ultrasound, Mifegymiso, bereavement training)
- 16. Do you feel there is a unique midwifery model of care for pregnancy loss? What does/would a model look like?
- 17. Are you able to meet your clients' needs with respect to EPL care?
- 18. Do you feel there are any barriers to providing midwifery miscarriage care and support?
  - If so, what are they? AND What types of organizational or policy support would help midwives in their efforts in providing early miscarriage care?
- 19. Is there anything that you would like to add?

#### Appendix J – Participant Feedback Letter



**FACULTY OF APPLIED HEALTH SCIENCES** | School of Public Health and Health Systems 519-888-4567 | fax 519-746-6776 uwaterloo.ca/public-health-and-health-systems

#### Dear Participant,

I would like to thank you for your participation in this study entitled *Navigating early pregnancy loss within Ontario's healthcare system: A qualitative exploratory study of midwives and their clients*. As a reminder, the purpose of this study was to explore the experiences of both midwives and their clients in providing and receiving healthcare for early miscarriage (less than 14 wks. gestation) in the Ontario context. The findings from this study will contribute to a better understanding of the midwifery model of care for early miscarriage, how this model is experienced by those providing and using midwifery care, and how it fits within the larger maternity care system context.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#41475). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

For all other questions related to the study, please contact:

Angela Freeman at or <a href="mailto:ar2freeman@uwaterloo.ca">ar2freeman@uwaterloo.ca</a>;

or Dr. Elena Neiterman at (510) 888-4567 ext. 38221 or eneiterman@uwaterloo.ca

Your participation in this study is voluntary, but and should you want to withdraw your participation you must do this prior to two weeks following your interview. Any data pertaining to you as an individual participant will be kept secure and confidential, and any quotes used for publication will be made anonymous.

Once all the data are collected and analyzed a summary of findings will be made available with an anticipated completion of July 2020. The results of this study may additionally be shared with the research community and policy makers through seminars, conferences, presentations, reports and journal articles. If you would like to receive the summary of findings, or would like more study information, please contact Angela Freeman at the contact information above.

Sincerely,

Angela Freeman, RM, MSc Candidate School of Public Health and Health Systems Faculty of Applied Health Studies University of Waterloo Waterloo, Ontario ar2freeman@uwaterloo.ca



#### **Appendix K – Resources for Participants**



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## **List of Resources for Participants**

For Emotional Support, Counseling, Information and Peer-groups:

Pregnancy and Infant Loss Network (PAIL Network): pailnetwork.ca and 416-480-5330 or 1-844-772-9388

Bereaved Families of Ontario: www.bfotoronto.ca and 416-440-0290 or 1-800-236-6364

For questions about midwifery care (i.e., scope of practice, finding a midwife)

College of Midwives of Ontario: www.cmo.on.ca

Association of Ontario Midwives: www.ontariomidwives.ca

For healthcare advice:

**Telehealth Ontario: 1-866-797-0000, TTY – 1866-797-0007** 

#### Resources for Mental Health:

ConnexOntario: <a href="http://www.connexontario.ca/">http://www.connexontario.ca/</a> and 1-866-531-2600 For up-to-date community-based information and a chat line where you can talk to someone to get more information.

IF you are in a mental health crisis call 911 or go to your nearest emergency department.