

Improving Access, Understanding, and Dignity During Miscarriage Recovery
in British Columbia, Canada
by
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Dedication: For the children we love, both those that are with us earthside and the ones with us in spirit, and the many families who have navigated pregnancy loss.

Abstract

Approximately 15–25% of pregnancies end in miscarriage, with more than 15,000 miscarriages occurring annually in British Columbia (BC), Canada (Perinatal Services BC, 2022; Public Health Agency of Canada, 2017). Despite the significant rates of loss, research and health care services for pregnancy loss remain scarce in BC. This research took a patient-oriented methodological approach alongside people with lived/living experiences of miscarriage recovery in BC to evaluate access to health care during pregnancy loss, societal understanding of miscarriage, and treatment options that foreground dignity. The mixed methods design of this research included policy research on prenatal care guidelines, policy research on provincial and territorial employment legislation for bereavement leave, semi-structured interviews (n = 27), and a discovery action dialogue (n = 4). The findings of this research demonstrate the need for improved prenatal care guidelines for early pregnancy loss, follow-up care after a miscarriage, mental health screening and supports, and bereavement leave legislation. This article includes recommendations to improve equitable access to pregnancy loss care, bereavement leave legislation, and future research in this area.

Keywords: Miscarriage, pregnancy loss, social determinants of health, health equity, patient-oriented research

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Introduction

Approximately 15–25% of pregnancies end in miscarriage (Public Health Agency of Canada, 2017), which is defined in Canada as the spontaneous death of an embryo or fetus before 20 weeks gestation (Perinatal Services BC, 2022; Public Health Agency of Canada, 2017). More than 15,000 miscarriages occurring annually in British Columbia (BC), Canada and an estimated 23 million miscarriages occurring each year globally (Perinatal Services BC, 2022; Quenby et al., 2021). Despite the significant rates of loss, research and health care services for pregnancy loss remain scarce in BC. Access to pregnancy loss care in Canada is matrixed and siloed, with health care systems managed at the provincial/territorial and regional levels, versus operating as national programs. Furthermore, actual rates are unknown because Canada does not have a national mechanism for monitoring and reporting miscarriages. Mental health care is one of the critical gaps in miscarriage support; parents have reported prolonged grief, depression, anxiety, post-traumatic stress disorder (PTSD), substance use, and suicide (Beutel et al., 1995; Brier, 2008; deMontigny et al., 2017; Korenromp et al., 2005; Kukulskienė & Žemaitienė, 2022; Kulathilaka et al., 2016; Lind & Deveau, 2017; Lok & Neugebauer, 2007; Quenby et al., 2021; Weng et al., 2018). On average, mental health recovery from pregnancy loss may take two to four years; however, it may take longer (Van Aerde, 2001). For example, people who become pregnant after a loss may experience heightened fear and anxiety (Fertl et al., 2009). While the majority of psychological research related to miscarriage has involved female participants, miscarriage may also negatively impact the mental health of partners (Meaney et al., 2017), including men, same-sex partners, and non-binary partners, as well as children and other members within the family unit. To aid recovery and future reproductive outcomes, improvements are needed within the health care system, including structure, monitoring, and programming underpinned by access, understanding, and dignity.

Recovery from miscarriage may also be impacted by not knowing why the miscarriage occurred. While chromosomal abnormalities account for approximately 50–60% of miscarriages (Hardy et al., 2016; Regan, 2018; Stanford Children’s Health, 2022), other risk factors include problems with the endometrium (uterus lining), structural abnormalities with the uterus and cervix, vaginal microbiota, hormones, blood conditions, stem cell count in the womb, history of recurrent miscarriages, sperm DNA damage, congenital anomalies, multifetal pregnancy, female age (≥ 35) and male age (≥ 40), interpregnancy interval, female body mass index (i.e., very low or very high), infections, (co)morbidities, intimate partner violence (IPV), racial inequality in health care, environmental stressors (e.g., frequent exposure to air pollution, pesticides, and working long hours and/or night shifts), smoking, substance use, listeriosis (food poisoning), vitamin D deficiency, high vitamin A intake, and high caffeine intake, to name a few (Bastos Maia et al., 2019; Grewal et al., 2022; Public Health Agency of Canada, 2017; Quenby et al., 2021; Regan, 2018; Sundermann et al., 2017; Tamblyn et al., 2022; Tewary et al., 2020; Wang et al., 2021; World Health Organization, 2016). Moreover, pregnancy loss contributes to an epidemiological, physical, psychological, and economic burden that requires further research and resources (Quenby et al., 2021). As CEO Jane Brewin of Tommy’s National Centre for Miscarriage Research challenges the *not preventable* miscarriage narrative, “For far too long it has often been said by many health professionals that miscarriage is not preventable, and parents have been left with little hope given the paucity of treatment options available” (Stephenson, 2020). When testing and treatment options are sparse or entirely not available to patients, this may impact both miscarriage recovery and future reproductive outcomes.

Despite being a wealthy country, Canada continues to have significant access issues and equity barriers in health care (Raphael et al., 2020), and the determinants of health underpinning recovery from pregnancy loss are particularly layered and complex due to under-resourced support services despite the high rates of loss (Yang et al., 2022). These

determinants of health include social systems and economic, legal, political, health care, educational, cultural, and religious subsystems; socioecological systems (e.g., environmental conditions and policies); living and working conditions; social relationships and networks (e.g., with family, community, etc.); individual behaviours; and innate traits and characteristics (e.g., biological and genetic factors, sex, age, and ethnicity) (Institute of Medicine et al., 2010). As such, social determinants of health (SDOH) play a significant role in shaping pregnancy loss health outcomes (McGibbon & McPherson, 2011; Raphael et al., 2020). For example, patients in BC are commonly told that testing for possible causes will only be offered after three or more miscarriages (HealthLink BC, 2022). Yet, according to the Executive Director of the United Nations Population Fund Dr. Natalia Kanem, reproductive rights should include “support in how to become pregnant, and care and counselling in the case of a miscarriage or for women suffering post-partum depression” (n.d.). When reproductive rights are restricted by health systems, the human right to health is not attainable for all (World Health Organization, 2022), including those experiencing pregnancy loss and other causes of infertility. This research study explores health equity barriers to pregnancy loss care from a SDOH lens, with particular interest in access to affordable, quality health services; social inclusion and non-discrimination; and income protection and job security during miscarriage recovery, such as access to paid bereavement leave and other employment standards. When there are barriers to each of these determinants, health equity is challenged during recovery from pregnancy loss and subsequent reproductive attempts. Without targeted research and improved pregnancy loss care, patients and their partners will continue to struggle with under-resourced support services, face high rates of pregnancy loss, and endure the devastating mental health challenges that may follow this loss—restricting the human right to health. This research aims to improve access to health care during pregnancy loss, societal understanding of miscarriage, and treatment options that foreground dignity.

Reflexivity Statement

Expecting our first child, my partner and I learned we had a delayed miscarriage during our first prenatal ultrasound appointment at about 11–12 weeks into the pregnancy on December 22, 2020. There was no heartbeat, and we were later told our little one had likely stopped developing a few weeks earlier. We were both shattered. While I had never felt pressure from a “biological clock” to become pregnant, I knew I wanted to start a family with my partner who longed to be a dad for years before we met. When I became pregnant at 32, I immediately started loving our baby. This was my first pregnancy loss, and my partner’s third recurrent loss (two from a previous marriage and then one with me), with no previously born children. While *missed* or *silent miscarriage* are more commonly used terms in Canada, I prefer the less frequently used term *delayed miscarriage*, which I feel more accurately represents a miscarriage that is diagnosed by ultrasound. For me, the words “missed” and “silent” were misleading for what turned out to be a first delayed and then prolonged loss due to the complications that followed.

Instead of bringing home our first baby’s ultrasound photo to share with family and friends over the holidays, I, supported by my partner, needed to decide which treatment option to select—expectant (natural/wait and see), medical (medication-assisted), or surgical management (dilation and curettage [D&C]). Because it was nearly Christmas, I opted for medical management, which involved self-administering Mifepristone and Misoprostol (MifeMiso). That was the last I heard from my maternity physician, with no further follow-up. Thankfully, another physician had joined us in the consult to discuss the treatment options, and he oversaw my file as I continued to bleed for over a month before being referred for a follow-up ultrasound to check if my body had retained pregnancy tissues. Shortly after that, I was scheduled for a D&C at our local hospital. According to one study, 17% of people who take MifeMiso will require surgical intervention for an incomplete miscarriage (Chu et al., 2020). By

then, I was both physically and mentally exhausted. We were then unable to reconceive and referred to a fertility clinic in the spring of 2022, where we learned that both my fallopian tubes had become blocked. My lived experience navigating pregnancy loss, post-miscarriage complications, and secondary infertility challenges, along with the women I met along the way who shared their own stories about pregnancy loss, led me to this research. Now a new mom to our first earthside baby, I understand how recovery from pregnancy loss is predicated on multiple intersecting determinants and that a “rainbow baby” does not replace or erase the first baby we lost.

Theoretical Framework

The pragmatism worldview or paradigm (Biesta, 2010; Cersosimo, 2020; Dewey, 2004; Frega & Carreira da Silva, 2011; Morgan, 2014) underpins this research through a social sciences and complexity ontology (as contrasted with a biomedical ontology), an intersubjectivity (relating experiences) and intersectionality (intersecting [dis]advantages) epistemology, and a co-creative axiology as a way to support miscarriage recovery and policy recommendations through integrated health care and SDOH. In research, paradigms refer to worldviews/ perspectives (Mathison, 2005). The pragmatism paradigm has a worldview that the nature of reality IS historically relational, yet ever-changing (Cersosimo, 2020). As such, pragmatic inquiry is not simply mixed methods; it is a meta-paradigmatic perspective that looks beyond paradigmatic boundaries to solve real-world problems.

As asserted by Biesta (2010), pragmatism “does away with an alleged hierarchy between different knowledges” (p. 112), recognizing there are many diverse ways of knowing or epistemologies. Enabling knowledge sharing and action, the value or axiology of pragmatic research is centered on solving real-world, social problems. To advance pregnancy loss care, we need to look at the whole and not merely separate parts of the health care system, as well

as SDOH (McGibbon & McPherson, 2011; Raphael et al., 2020; World Health Organization, n.d.). Congruent with complexity theory, these “systems are over-lapping and non-nested” (Walby, 2007, p. 454), with change being nonlinear and requiring transdisciplinary approaches.

Methodology

This research took a patient-oriented methodological approach that employed participatory community engagement with people who have lived/living experience of miscarriage recovery in BC to evaluate access to health care during pregnancy loss, societal understanding of miscarriage, and treatment options that foreground dignity (Canadian Institutes of Health Research, 2018; Coghlan & Brydon-Miller, 2014; Given, 2008; Root, 2007). The values of community-engaged research are *with* and *for* community, honouring the principle of “Don’t do anything about me without me” (Pascale et al., 2010, p. 197). The patient-oriented research approach engages patients and partners in the research process to inform inter- and transdisciplinary pregnancy loss care (Canadian Institutes of Health Research, 2018). This inter- and transdisciplinary approach enables the co-production of knowledge by bringing together people from diverse lived/living experiences and different perspectives (Schuttenberg & Guth, 2015). Transdisciplinarity involves looking at the current state (systems knowledge), understanding how things could be different through change (target knowledge), and taking actions to bridge the current state and the end goal (transformation knowledge) (Hadorn et al., 2008). As such, transdisciplinary approaches go beyond disciplinary boundaries to create new ways of doing things (Choi & Pak, 2006). Moreover, this research brings people together to improve: (1) health research on miscarriage recovery, (2) access to integrated health care services, and (3) equitable employment standards in BC following pregnancy loss.

Methods

This research study was approved by the Royal Roads University Research Ethics Board. The study involved two phases: Phase 1 – policy analysis of provincial and national prenatal care guidelines and policy analysis of provincial and territorial bereavement leave legislation in Canada, and Phase 2 – interviews and discovery action dialogues with people who have lived/living experience of miscarriage recovery in BC. The inductive nature of this research asked the following questions: (a) in what ways have patients and families who have experienced one or more miscarriages been positively supported during miscarriage recovery in BC—without access to exclusive resources?; and (b) what gaps in BC's health care system and employment standards currently present barriers to patients and families during miscarriage recovery?

Phase 1: Policy Analysis of Prenatal Care Guidelines and Bereavement Leave Legislation

Provincial and national prenatal care guidelines that included content on pregnancy loss, and/or pregnancy complications with a potential outcome of pregnancy loss, were analyzed. This included four guidelines from Perinatal Services BC (provincial level) and one guideline from the Public Health Agency of Canada (national level). Bereavement leave legislations from British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland and Labrador, the Northwest Territories, and the Yukon were analyzed to determine the inclusion/exclusion of pregnancy loss coverage; Nunavut did not have bereavement leave legislation at the time of the analysis. The data was analyzed thematically in NVivo, including the application of sex and gender-based analysis (Hankivsky, 2012), intersectionality-based policy analysis (Hankivsky et al., 2010, 2014), and positive deviance (the identification of positive outliers) (Pascale et al., 2010; Singhal, 2015; Singhal et al., 2010, 2014; Sternin, 2002) to inform patient and family-centered pregnancy loss care.

Phase 2: Interviews and Discovery Action Dialogues

Participants with lived/living experience of miscarriage recovery were recruited through outreach to health and community organizations across BC in remote, rural, and urban locations, as well as snowball sampling (Merriam & Tisdell, 2015). Participants who provided informed consent were invited to select their preference of participating in an interview (one-on-one or with their partner) and/or a discovery action dialogue with other participants (Lipmanowicz & McCandless, 2013). Congruent with a trauma-informed lens, participants were provided with the question guide and mental health support information ahead of the interviews and discovery action dialogue. The interviews were conducted virtually between August and December 2022. The discovery action dialogue took place over video conferencing in November 2022. The guide for the interviews and discovery action dialogue included questions on available services and supports, barriers/challenges, and health system transformation. The interviews and discovery action dialogue were transcribed, and the data was analyzed thematically in NVivo using a combination of priori and emerging codes. Upon completion of Phase 1 and 2, a policy brief was drafted and shared with participants for member checking and feedback loops prior to disseminating the findings to government agencies and health authorities.

Results and Discussion

Prenatal Care Guidelines

This research analyzed prenatal care guidelines by the Public Health Agency of Canada and Perinatal Services BC. At the national level, this included the fifth and latest version of the *Family-Centred Maternity and Newborn Care: National Guidelines* for pregnancy loss information published by the Public Health Agency of Canada in 2017, with modifications made to select chapters and supplementary materials in 2018, 2019, 2020, and 2022. While these

guidelines are not considered clinical practice guidelines (CPGs), they “are intended to assist health care organizations, providers, program planners, policy makers, administrators and families to propose, plan, implement and evaluate maternal and newborn health care policies and practices” (Public Health Agency of Canada, 2017).

In addition to information on chromosomal abnormalities, the guideline discusses some of the risk factors associated with pregnancy loss; however, other critical and diagnosable risk factors are not discussed (e.g., other morbidities and comorbidities, problems with the endometrium, structural abnormalities with the uterus and cervix, vaginal microbiota, hormones, blood conditions, etc.), including male factors such as sperm DNA damage. The inclusion of these other diagnosable risk factors would support dissemination to HCPs, and thus, aid patients during recovery and future reproductive outcomes by knowing, when possible, what happened. These guidelines also contain a comprehensive chapter on loss and grief, with emphasis on compassionate care and communication strategies. In addition to noting prolonged grief, clinical depression, anxiety disorders, and PTSD as potential mental impacts from pregnancy loss, substance use and suicide risks (Kukulskienė & Žemaitienė, 2022; Kulathilaka et al., 2016; Weng et al., 2018; Quenby et al., 2021) should also be included to improve mental health screening and follow-up supports after pregnancy loss.

Perinatal Services BC published a *Maternity Care Pathway* in 2010. This historical pathway document included important information for HCPs, such as discussing early pregnancy loss with patients at the first or subsequent visit, as well as screening and providing additional care to high-risk patients. This information is no longer included in current guidelines. The *Population and Public Health Prenatal Care Pathway* published by Perinatal Services BC in 2014 replaced this guideline and was developed as a tool for public health nurses (PHN). While this iteration includes important information on how to assess patients and partners for general health, grieving reactions, social supports, and PHN follow-up and support, the findings from the

lived/living experiences subsection of this study suggest patients are rarely supported by PHNs following a pregnancy loss in BC. Physicians and midwives more commonly provide follow-up care after a miscarriage. As such, the utility of this guideline is limited by its narrow target knowledge user audience of PHNs. Additionally, this guideline uses gendered language (e.g., women, woman, she, her) while referring to the patient, and therefore, is not inclusive of non-binary, Two-Spirit, and transgender persons (e.g., a person who was biologically born a female and can carry a pregnancy that now identifies as a man). Using non-gendered language (e.g., person carrying the pregnancy and their partner) in guidelines recognizes sex and gender diversity amongst patients.

The *Perinatal Mortality Guideline* directed at a broader HCP knowledge user audience and published by Perinatal Services BC in 2017 does not contain any information on miscarriage, with the exception of a definition for “abortus” (i.e., a fetus that dies before 20 weeks) which is then not used in the guideline itself. In contrast, this guideline provides comprehensive information on stillbirth (i.e., a fetus that dies after 20 weeks), including an evaluation and care checklist. The absence of evaluation and care recommendations for pregnancy losses before 20 weeks can begin to explain the lack of consistency in diagnoses and follow-up care for miscarriage discussed in the lived/living experiences subsection of this article. Similarly, the *Standards for Obstetrical Ultrasound Assessments* published by Perinatal Services BC in 2015, which although having a section on abnormal or unexpected findings, does not include any mention of miscarriage, such as missed/delayed miscarriage that is commonly discovered during a prenatal ultrasound and requires compassionate care and communication (Van Tuyl, in press).

Lived/Living Experiences of Miscarriage Recovery in BC

Demographics

Twenty-seven people participated in this study's semi-structured interviews, including 26 people who carried the pregnancy(ies) and one partner. Four of these people also opted to participate in a discovery action dialogue. Of the participants carrying the pregnancy(ies) (n = 26), 42% (n = 11) had one self-reported miscarriage, 42% (n = 11) had two self-reported miscarriages, 12% (n = 3) had three self-reported miscarriages, and 4% (n = 1) had four self-reported miscarriages. Additionally, 27% (n = 7) also experienced other types of pregnancy/baby loss(es), such as chemical pregnancy¹, ectopic pregnancy, embryo loss following in vitro fertilization (IVF) treatment, or infant loss. (While stillbirth, termination for medical reasons, and molar pregnancy were not reported as subsequent losses in this research study, these are additional types of pregnancy/baby loss.) Participants lived in the Interior Health (n = 5), Fraser Health (n = 4), Vancouver Coastal Health (n = 5), Vancouver Island Health (n = 12), and Northern Health (n = 1) regions of BC during the time of their miscarriage and/or part of the recovery process, including six participants who experienced one or more miscarriages in another province/territory or country. Participation by geographical setting included urban (n = 19), rural (n = 6), and remote (n = 2).

¹ Chemical pregnancy is a miscarriage before five weeks (Tommy's National Centre for Miscarriage Research, 2022a), although not all medical definitions recognize it as a miscarriage. Participants who self-reported a chemical pregnancy(ies) in this study described their chemical pregnancy as a different type of loss than their other miscarriage(s), which may be due to how it was defined to them by a HCP.

Health Care Access

Lack of Follow-up Care.

*“I honestly felt like they dropped me like I was hot...
as soon as there was no living baby inside me anymore.”*

Participants commonly reported a lack of, or complete absence of, follow-up care following miscarriage across remote, rural, and urban locations. Examples included the discontinuation of care by their HCP immediately after miscarriage, limited or incorrect information on what to expect next, inconsistencies in ultrasound referrals where only some participants were offered ultrasounds to check for incomplete miscarriages, and a general lack of mental health screening and supports. For patients who reported complications following miscarriage, incomplete miscarriages, severe hemorrhaging, and infection were reported. These findings align with the lack of prenatal care guidelines for pregnancy loss before 20 weeks. As previously asserted by Dugas & Slane, 2021, “Treating patients who experience pregnancy loss requires close coordination between all members of the care team.” Participants also highlighted how different people require different amounts of follow-up care; some required follow-up care immediately, while others would have benefited from subsequent follow-ups. As one participant shared after struggling with the loss for six months on her own, subsequent follow-ups may be required for several months, including past the expected due date of the baby they lost. The differing follow-up care needs amongst patients highlights the importance of engaging the patient and partner in decisions on initial and subsequent follow-up care. As noted by another participant, follow-up care should be provided alongside translation services for people whose first language is another language than English. For participants who did receive

thorough prenatal and follow-up care, they credited a particular HCP provider that led with compassionate care values and practices.

Limited Mental Health Services and Supports.

“There was one day my husband just said, ‘Let’s just try to get out of bed today’... I’ve never experienced depression or grief like that. I got out of the bed, and I showered and that was the accomplishment. And then I went back to bed.”

The results from this study confirm previous research findings on the mental health implications of miscarriage and other types of pregnancy loss, including prolonged grief, depression, anxiety, PTSD, substance use, and suicide (Beutel et al., 1995; Brier, 2008; deMontigny et al., 2017; Korenromp et al., 2005; Kukulskienė & Žemaitienė, 2022; Kulathilaka et al., 2016; Lind & Deveau, 2017; Lok & Neugebauer, 2007; Quenby et al., 2021; Weng et al., 2018). Additionally, some participants experienced shock, anger, and panic attacks. Yet, participants were rarely referred to mental health services by their HCPs. Participants also emphasized the importance of having a choice in the mental health services they receive, such as counselling (one-on-one, couples, or as a family), peer support groups (e.g., by the health authority, midwife clinic, or a non-profit providing pregnancy loss support), or psychologists and psychiatrists depending on the need and preferences of the patient and partner. Additionally, some participants highlighted how couples might require support understanding how one another may grieve differently. Various participants also expressed the importance of affordable and accessible mental health services. As summarized by one participant, “Mental health care is health care, and it needs to be covered. Mental health needs to be free.” Moreover, follow-up

care for miscarriage should include mental health screening, and if needed, navigation support to accessible mental health services.

For patients who experienced miscarriage during the COVID-19 pandemic, it appears that additional stress and trauma may have been caused by restrictions that did not allow partners to attend appointments. As one participant shared, her partner was not allowed to join her during an ultrasound appointment to check if *their* baby still had a heartbeat after she started bleeding in the second trimester, nor was her partner allowed to be in-hospital during the D&C. Prenatal ultrasound protocols could be changed by health authorities to recognize the equal rights of both parents during prenatal care (Van Tuyl, in press).

For some, impacts on their mental health continued through to future pregnancies or until they had no other choice than to stop trying to conceive after recurrent losses and infertility. As one participant shared after two miscarriages, one full-term birth, and while pregnant with a second full-term birth, “I’m scared of my stomach. It’s like touching my belly, and there’s holding so much trauma. It’s literally like life and death in there.” Furthermore, some patients were denied having their progesterone levels checked and/or progesterone prescribed after requesting it following recurrent miscarriages, despite its wide usage in the United Kingdom to reduce the risk of recurrent losses (Tommy’s National Centre for Miscarriage Research, 2022b). The denial of having progesterone levels checked suggests restrictions to reproductive rights, where patients’ reproductive freedoms are limited by health system interference (World Health Organization, 2022). These findings highlight the need for integrated health care services that support the whole person, including their reproductive rights and mental health.

Practitioner Discourse and Terminology on Pregnancy Loss.

“For me and my husband, it was a baby.”

What HCPs say also impacts patients and partners during miscarriage recovery. Patients from this study shared how terminology such as *spontaneous abortion*, *missed abortion*, *products of conception*, and to “confirm” one’s miscarriage did not recognize the significant loss they went through. As a participant shared:

I don't think anybody ever asked me the whole time was what I wanted the pregnancy to be referred to as. Like one doctor explained to me it's called a missed abortion, and another doctor was calling it like the products of conception. It was just like different doctors are using different words. I'd wish they'd just said like, what would you like me to refer to your pregnancy as a baby or something else. Because for me and my husband, it was a baby. So hearing it talked about in all these different ways was not helpful.

Asking patients what terminology they would like used while referring to their loss can better support their recovery. Additionally, general pregnancy loss discourse matters to patients. During an upsetting encounter with her family doctor, a patient was told she had “no idea what it’s like to have a rough life” and that she needed “to stop living in a fairytale land where every pregnancy ends up with a healthy baby.” Responses from HCPs that minimize patients’ trauma following pregnancy loss are particularly problematic because the absence of a psychologically safe medical environment silences patients from disclosing their health concerns, and potentially, seeking mental health supports, if needed.

Pregnancy Loss Stigma

“It doesn't feel like culturally we have enough permission to be honest about how when it happened—when miscarriage happens, how it goes.”

In relation to the current culture surrounding pregnancy loss in Canada, various participants spoke about wanting the “taboo” and “stigma” to change. Some participants also noted generational differences from previous generations in a willingness to talk about pregnancy loss and infertility. As such, some participants looked to longer-standing cultures to recognize the loss of their baby. Learning from First Nations traditions and ceremonies, one couple held a candle lighting ceremony. A Jizo Bodhisattva statue, known as the protector of children and travelers in Buddhism, was placed inside the home of another couple. These findings relate to previous claims that North American culture does not spend enough time talking about death and grief (Johnson, 2004; Samuel, 2013). As various participants shared, pregnancy loss stigma is particularly challenging for men. As one participant shared, “If women are finding it woefully inadequate, I think it's even worse for men, and a lack of acknowledgment that they lose a possibility. They lose a life.” Another participant shared, “There was an outpouring of like awkward but still support for me. But there was really nothing for him like people, even his own friends or family, would ask how I was doing but never really checked in on him.” As previously asserted by Tommy's National Centre for Miscarriage Research and Miller et al. (2019), these findings confirm how the cultural shift related to pregnancy loss needs to support both patients and partners, including access to integrated health care for pregnancy loss, the understanding that reproductive rights are a right to health, and dignified treatment and prevention options.

Personal, Interpersonal, and Informal Supports

“I found that the more I mentioned what happened, the more women would tell me that they had gone through it as well. And with every shared intimate story, I felt a little bit better.”

In the absence of more comprehensive publicly-funded supports for pregnancy loss, patients and their partners frequently turn to personal, interpersonal, and other informal supports during the recovery process. Participants commonly noted relationships with their partner, family, and/or friends as interpersonal supports. Some participants also noted that not all partners, family, and friends were supportive. Connecting with other people who had lived/living experience of pregnancy loss—whether a friend, family member, neighbour, or colleague—was also commonly mentioned as an important interpersonal support. In turn, participants often went on to engage in reciprocity and support other people who experienced pregnancy loss after them, both within their personal and professional circles.

In addition to relationships, participants often sought ways to support themselves through the grieving process, such as speaking with a counselor, therapeutic writing (e.g., journaling, poetry), reading (+/- engaging with) pregnancy loss conversations online, drawing, meditating, doing yoga, and participating in a charity run for loss and infertility. With cremation or other ceremonial services rarely offered to them by their HCPs, the majority of participants sought artifacts to remember their baby, such as pregnancy tests, ultrasound or pregnancy photos, a baby outfit, a stuffed animal, a handmade rainbow banner, custom jewelry with the baby’s initials or birth stone, artwork, a butterfly token and balloons, sympathy cards, a plant or dried flowers, candles, and Christmas ornaments. These are all examples of positive deviance,

where patients and partners sought ways to acknowledge their loss amidst systems that commonly did not provide support.

Employer Supports

*“My boss was amazing...I feel so grateful for him and really loyal to him now,
as a result of how he treated me...There is no impact on my paycheck.
There is no deduction to my vacation days or bereavement days...
They gave me paid days to just focus and heal.”*

For patients who were employed at the time of their miscarriage, policies and support from employers varied. While flexibility is appreciated by some employees, unstructured policies can also make it difficult for employees to determine unwritten company expectations for bereavement leave. “I actually found that harder than if there had been like a structured certain amount of time you get for bereavement,” shared a participant. Another participant recalled being asked to return to work after two days off, before she was ready to go back. A HCP who miscarried and then returned to work quickly to support her own patients shared, “I remember I didn't call in sick...but I do remember being at work saying to myself, I can't believe I'm here and nobody knows what my body is currently undergoing.” Some employees may prefer to return to work soon after. “I also remember feeling like work is the thing that's helping me keep myself together right now,” shared another participant. These findings suggest the importance of respecting *choice* following a loss—some people will need to take time off while others will prefer to return to work. There are also some employers that exceed legislated employment standards to support employees after pregnancy loss. Compassionate employers that provided people with two to three weeks' paid leave were recognized as important supports during

recovery. These responses from participants indicate the importance of employers understanding employment standards, setting clear company policies, and helping employees learn what is available to them (e.g., work from home options, legislated bereavement and sick leaves, company policies that may exceed legislated leaves, extended health leave benefits, and employment insurance).

Bereavement Leave Employment Standards

Bereavement leave in Canada differs across provinces and territories according to the employment/labour standards legislated for the respective jurisdictions (see Table 1). In BC (at the time of publication) as stipulated by the Employment Standards Act under section 53, “An employee is entitled to up to 3 days of unpaid leave on the death of a member of the employee's immediate family” (Government of British Columbia, 2022). BC’s bereavement leave is unpaid and does not include explicit language on pregnancy loss. In contrast, some provinces provide a combination of paid and unpaid bereavement leave. The lack of explicit pregnancy loss language in BC’s and other jurisdictional employment legislation means employees and employers need to interpret if an unborn child is included in the “family member” definition. Including explicit pregnancy loss language in bereavement leave legislation supports employees and their employers in knowing they are allowed to take time off from work. This language should also be equitable, recognizing all pregnancy losses regardless of gestation length. For example, Quebec’s legislation fails to do this by only recognizing pregnancy losses at or after 20 weeks of gestation. Additionally, the absence of paid bereavement leave for pregnancy loss (and all other losses) means some people will not be able to afford to take time away from work to grieve a loved one. A more equitable example of bereavement leave legislation is in New Zealand where three days *paid* leave are provided *per* bereavement (New Zealand

Government, 2022). While grieving processes generally extend far beyond three days (Van Aerde, 2001), bereavement leave can be combined with paid sick leave as needed through BC's legislated five paid sick days, Canada's employment insurance (EI), and if provided by an employer, extended health leave benefits.

Table 1

Bereavement Leave Legislation in Canada (at the time of publication)

Jurisdiction	Allocation	Does the policy mention pregnancy loss?
British Columbia	3 days unpaid	No
Alberta	3 days unpaid	Yes
Saskatchewan	5 days unpaid	No
Manitoba	3 days unpaid	No
Ontario	2 days unpaid	No
Quebec	2 days paid + 3 days unpaid for immediate family only, otherwise 1 day unpaid	Yes, but only for 20+ weeks of gestation
New Brunswick	5 days unpaid	No
Nova Scotia	5 days unpaid	No
Prince Edward Island	1 day paid + 2 days unpaid for immediate family only, otherwise 3 days unpaid	Yes
Newfoundland and Labrador	1 day paid leave + 2 days unpaid	No
Nunavut	No bereavement leave policy	N/A
Northwest Territories	3 days unpaid within community; 7 days unpaid if travel is required	No
Yukon	One week unpaid	No

Limitations

Despite efforts to recruit participants from the Northern Health region of BC, only one participant from this health region expressed interest to participate in the study. Future research would benefit from more patients participating from the Northern Health region to further explore barriers to pregnancy loss care in remote and rural locations. Similarly, despite efforts to recruit more partners (opposite sex, same sex, and non-binary) to participate alongside the patient, the

majority of patients (25 out of 26) opted to participate on their own and without their partner. As such, the results of this research largely reflect the experience of the person who carried the pregnancy. Future research could consider explicitly exploring couples' experiences of pregnancy loss.

Conclusions

In BC, there are significant gaps in prenatal care guidelines between stillbirth (pregnancy loss after 20 weeks) and early pregnancy loss (before 20 weeks), with guidelines for miscarriage and other forms of early pregnancy loss not fully developed. The lack of prenatal care guidelines for miscarriage and other forms of early pregnancy loss communicates sociocultural incongruities that reflect a hierarchy of care; miscarriages and other forms of early pregnancy loss do not receive the same level of health care access, societal understanding, and dignified treatment options as stillbirths. A hierarchy of care for pregnancy loss is problematic because it does not recognize the mental health impact of miscarriages and other forms of early pregnancy loss on patients and partners. Prenatal guidelines should be updated to provide equitable care to people who experience early pregnancy losses, including improved continuation of care by HCPs after a loss, a debrief on what happened and what to expect next, consistency in ultrasound referrals to check for complications, and mental health screening and supports. Additionally, BC's bereavement leave legislation under the Employment Standards Act does not currently include pregnancy loss language, leaving employees and employers to interpret if an unborn child is included in the "family member" definition. Amending the Employment Standards Act legislation on bereavement leave to include explicit pregnancy loss language, and ideally, introduce paid bereavement leave for all types of losses, would improve equitable access to paid time off while grieving the loss of a loved one, regardless of socioeconomic status. The mental health implications of pregnancy loss also highlight issues in

only offering testing after three recurrent losses. Instead, BC and Canada can adopt existing recommendations to start testing sooner, including improved screening and care for high-risk patients (Tommy's National Centre for Miscarriage Research, 2021). This effort should be supported by Canada establishing a systemic and national-level mechanism for monitoring and reporting on pregnancy loss rates to improve research, policy, and patient care (Coomarasamy et al., 2021; Quenby et al., 2021). More research on risk factors for pregnancy loss and prevention is also required. As shown in Figure 1, pregnancy loss care and prevention require an integrated health care approach to improve health equity by considering intersectional factors and supporting the whole person, including their reproductive rights and mental health. Further work is required to investigate and implement these SDOH factors through an intersectional lens.

Figure 1

Improving Integrated Health Care for Pregnancy Loss in BC and Beyond



Dissertation Format and Knowledge Translation Plan

Royal Roads University provides Doctor of Social Sciences students with the option to complete their dissertation as a monograph or as a portfolio, consisting of three deliverables.

The dissertation by portfolio format is well-suited for this miscarriage recovery study that is

rooted in pragmatic research and centered on solving real-world problems. As such, the knowledge translation plan for this research endeavors to mobilize knowledge and contribute to capacity building by: (1) aiding miscarriage recovery through the identification and sharing of equitable pregnancy loss care practices and supports; and (2) presenting policy recommendations to improve prenatal care guidelines and employment standards for pregnancy loss. The following research outputs comprise the dissertation by portfolio deliverables: (a) an open-access journal publication, (b) a policy brief on pregnancy loss care in BC, and (c) a poster presentation at health conferences. Aligned with the applied nature of this research, these deliverables enable knowledge sharing to HCPs, community members, researchers, policymakers, and decision-makers.

Portfolio Deliverables

Journal Manuscript

Royal Roads University has a mandatory requirement for one of the portfolio deliverables to be a manuscript. *Women's Health*, a SAGE journal, was selected for this research's publication to highlight the health system changes needed to improve pregnancy loss care in BC. *Women's Health* is a peer-reviewed, "gold" open access journal publishing international research and theory in the field of women's health. Importantly, open access journals, such as *Women's Health*, enable research accessibility to non-academic community members who may not hold publication subscriptions. By publishing this research in *Women's Health*, HCPs, community organizations, community members, researchers, policy-makers, and decision-makers will have access to the research article at no cost to them.

Policy Brief

A policy brief on miscarriage recovery has been developed and will be disseminated to health authorities and government agencies to inform pregnancy loss care improvements and

policy development. The policy brief has been informed by patients' lived/living experiences with miscarriage recovery in BC, policy research on prenatal care guidelines, and policy research on bereavement leave legislation for Canada's provinces and territories. The policy brief underwent member checking with participants to provide comprehensive recommendations that consider intersectionality and sex and gender-based analysis principles. The policy brief will be sent to health authorities and government agencies involved in prenatal care, including but not limited to all BC health authorities, the Midwives Association of British Columbia, Perinatal Services BC, BC Women's Hospital and Health Centre, Women's Health Research Institute, BC Women's Health Foundation, BC Mental Health and Substance Use Services, BC Support Unit, Michael Smith Health Research BC, BC Ministry of Health/Minister of Health, BC Public Health, BC Ministry of Mental Health and Addictions, BC Ministry of Labour, Public Health Agency of Canada, and Health Canada. Through this deliverable, the intent is to mobilize further research and practical application for pregnancy loss care in BC and beyond.

Poster Presentation

With the goal of mobilizing the research findings to HCPs, researchers, and decision-makers working in women's health, a poster presentation was shared at the annual Women's Health Research Institute symposium on March 8, 2023 in Vancouver, BC. Aligned with this year's conference theme on mental health, the poster presentation highlighted the mental health implications of miscarriage, along with recommendations to improve pregnancy loss care and policy development. The conference was well-attended by HCPs, researchers, and decision-makers working in perinatal care, including but not limited to representatives from BC Women's Hospital and Health Centre, BC Mental Health and Substance Use Services, Perinatal Services BC, the Women's Health Research Institute, and the BC Women's Health Foundation. Building on this initial knowledge translation, these organizations will also receive the policy brief.

Additionally, the Women's Health Research Institute shared the poster presentation on their social media, which garnered additional interest from community members. To further disseminate information about the urban, rural, and remote geographical disparities experienced while receiving pregnancy loss care in BC, this poster presentation has also been accepted to the BC Rural Health Conference taking place in Whistler from June 2–4, 2023. Lastly, when the BC Support Unit's Putting Patients First Conference returns in 2023 (date TBD), a presentation will also be submitted for consideration at this patient-oriented research conference to reach additional HCPs, community organizations, community members, researchers, policymakers, and decision-makers.

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