

# Improving access, understanding, and dignity during miscarriage recovery in British Columbia, Canada: A patient-oriented research study

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Rana Van Tuyl 

## Abstract

**Background:** Approximately 15%–25% of clinical pregnancies end in miscarriage, with more than 15,000 miscarriages occurring annually in British Columbia, Canada. Despite the significant rates of loss, research and health care services for pregnancy loss remain scarce in British Columbia.

**Objectives:** This study aimed to (1) aid miscarriage recovery through the identification and sharing of equitable pregnancy loss care practices and supports and (2) present policy recommendations to improve prenatal care guidelines and employment standards for pregnancy loss.

**Design:** This research took a patient-oriented methodological approach alongside people with lived/living experience(s) of miscarriage recovery in British Columbia to evaluate access to health care during pregnancy loss, societal understanding of miscarriage, and treatment options that foreground dignity.

**Methods:** 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).

**Results:** 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.

**Conclusion:** This article includes recommendations to improve equitable access to pregnancy loss care, bereavement leave legislation, and future research in this area.

## Keywords

health equity, miscarriage, patient-oriented research, pregnancy loss, social determinants of health

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## Introduction

Approximately 15%–25% of clinical pregnancies end in miscarriage,<sup>1</sup> which is defined in Canada as the spontaneous death of an embryo or fetus before 20 weeks gestation.<sup>1,2</sup> More than 15,000 miscarriages occur annually in British Columbia (BC),<sup>2</sup> Canada and an estimated 23 million miscarriages occur each year globally.<sup>3</sup> 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 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; bereaved parents have reported

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Royal Roads University, Victoria, BC, Canada

### Corresponding author:

Rana Van Tuyl, Royal Roads University, 2005 Sooke Road, Victoria, BC V9B 5Y2, Canada.  
Email: rana.vantuyl@royalroads.ca



prolonged grief, depression, anxiety, post-traumatic stress disorder (PTSD), substance use, and suicide.<sup>3–12</sup> On average, mental health recovery from pregnancy loss takes 2–4 years; however, it may take longer.<sup>13</sup> For example, people who become pregnant after a loss may experience heightened fear and anxiety.<sup>14</sup> While the majority of psychological research related to miscarriage has involved female participants, miscarriage may also negatively impact the mental health of partners,<sup>15</sup> 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,<sup>16–18</sup> other risk factors include problems with the endometrium (uterus lining), structural abnormalities with the uterus or cervix, microbiota, hormones, blood conditions, stem cell count in the womb, prior history of miscarriage(s), sperm DNA damage, congenital anomalies, multifetal pregnancy, female age ( $\geq 35$  years) and male age ( $\geq 40$  years), 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.<sup>1,3,17,19–27</sup> Moreover, pregnancy loss contributes to an epidemiological, physical, psychological, and economic burden that requires further research and resources.<sup>3</sup> 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."<sup>28</sup> 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.<sup>29</sup> 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 behaviors; and innate traits and characteristics (e.g. biological and genetic factors, sex, age, and ethnicity).<sup>30</sup> 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.<sup>31</sup> As such, social determinants of health (SDOH) play a significant role in shaping health outcomes.<sup>29,32</sup> For example, patients in BC are commonly told that testing for possible causes will only be offered after three or more miscarriages; however, this guidance has recently been updated to allow patients to request testing after two or more consecutive losses.<sup>33</sup> Yet, according to the Executive Director of the United Nations Population Fund Dr Natalia Kanem,<sup>34</sup> 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." When reproductive rights are restricted by health systems, the human right to health is not attainable for all,<sup>35</sup> 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 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.<sup>36</sup> 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. This research aims to improve access to health care during pregnancy loss, societal understanding of miscarriage, and treatment options that foreground dignity.

### *Personal equipoise*

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 22 December 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 years, 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.<sup>37</sup> 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.

## Design

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.<sup>38–41</sup> The values of community-engaged research are *with* and *for* community, honoring the principle of “Don't do anything about me without me.”<sup>42</sup> The patient-oriented research approach engages patients and partners in the research process to inform pregnancy loss care.<sup>38</sup> This transdisciplinary approach enables the co-production of knowledge by bringing together people from diverse lived/living experiences and different perspectives.<sup>43</sup> 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).<sup>44</sup> As such, transdisciplinary approaches go beyond disciplinary boundaries to create new ways of doing things.<sup>45</sup> 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

### Procedure

People with lived/living experience(s) of miscarriage recovery were purposively recruited through outreach to health and community organizations across BC in remote, rural, and urban locations using physical posters and digital strategies (e.g. e-newsletters, emails, and social media), and snowball sampling.<sup>46</sup> The inclusion criteria were people with lived/living experience of miscarriage recovery in BC (stillbirth was not included in this study). Participants provided written consent; consent was reconfirmed verbally prior to starting the interviews and recorded accordingly. 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 patients. Discovery action dialogues help groups identify practices and behaviors that result in better outcomes to a common problem.<sup>47</sup> The question guide, which was used for the interviews and discovery action dialogue, was drafted by a researcher with lived experience of miscarriage and then reviewed by two researchers/people with lived experience of miscarriage and two additional researchers without lived experience. Minor changes were made (e.g. question wording and order) following the review. Congruent with a trauma-informed lens, participants were invited to contact the researcher with any questions they had ahead of participating, informed of the researcher's lived experience with miscarriage and reasons for conducting the research (policy development and practical application), and provided with the question guide and mental health information on free provincial, national, and international support services ahead of the interviews and discovery action dialogue. Van Tuyl, a female with lived experienced of miscarriage and a researcher with formal research training (PhD equivalent, Doctor of Social Sciences), conducted the interviews and discovery action dialogues. The interviews were conducted virtually and recorded through teleconferencing between August and December 2022. The majority of interviews were conducted within 1 h; however, some went longer as per the participant's request. The discovery action dialogue took place over teleconferencing for a 2-h duration in November 2022 and was recorded. Concurrently, prenatal care guidelines and employment/labor standard legislations were analyzed between June and November 2022. On completion of the policy research, interviews, and discovery action dialogue, a policy brief was drafted and shared with participants for member checking and feedback loops (in lieu of transcripts) prior

to disseminating the findings to government agencies and health authorities operating at the provincial and national levels.

### Data analysis/statistical analysis

This research used a mixed-methods design, including policy research of Perinatal Services BC and the Public Health Agency of Canada's prenatal care guidelines, policy research of provincial and territorial employment legislation for bereavement leave, semi-structured interviews (n=27), and a discovery action dialogue (n=4) with people who have lived/living experience(s) of miscarriage recovery in BC. Sample size and thematic saturation were achieved. Provincial and national prenatal care guidelines that contained content on miscarriage, and/or pregnancy complications with a potential outcome of miscarriage, were included in the analysis. This included four guidelines from Perinatal Services BC<sup>48-51</sup> (provincial level) and one guideline from the Public Health Agency of Canada (national level).<sup>1</sup> Bereavement leave legislations from British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland and Labrador, Northwest Territories, and 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.<sup>52-64</sup> 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 verbatim for analysis and coded by a researcher. The policies, interview transcripts, and discovery action dialogue transcript were analyzed thematically in NVivo using a coding tree of patient experiences, prenatal guidelines, and bereavement legislation with a combination of priori and emerging child codes,<sup>65</sup> including the application of sex- and gender-based analysis,<sup>66</sup> intersectionality-based policy analysis,<sup>67,68</sup> and positive deviance (the identification of positive outliers)<sup>42,69-72</sup> to inform patient- and family-centered pregnancy loss care. The findings from the different data sources were triangulated to identify and synthesize key findings by source type and then make health system transformation recommendations informed by all source types.

## Results

### 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-Centered Maternity and Newborn Care: National Guidelines* for pregnancy loss information

published by the Public Health Agency of Canada<sup>1</sup> 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, 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."<sup>1</sup> 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, microbiota, hormones, blood conditions, etc.), including male factors, such as sperm DNA damage. These guidelines also contain a comprehensive chapter on loss and grief, with emphasis on compassionate care and communication strategies. While prolonged grief, clinical depression, anxiety disorders, and PTSD are noted as potential mental health impacts from pregnancy loss in this guideline, substance use and suicide risks<sup>3,8,9,12</sup> are currently omitted.

Perinatal Services BC<sup>48</sup> published a *Maternity Care Pathway* in 2010. This historical pathway document included important information for health care providers (HCPs), such as discussing early pregnancy loss with patients at the first or subsequent visit, and 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<sup>49</sup> 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 in BC. As such, the utility of this guideline may be limited by its narrow target knowledge user audience of PHNs. In addition, 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).

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 limited definition for "abortus" (i.e. a fetus that dies before 20 weeks [embryonic stage omitted from definition]), which is then not used



**Table 1.** Patient experience themes and subthemes.

Themes	Subthemes
Health care access	<ul style="list-style-type: none"> <li>• Lack of follow-up care</li> <li>• Limited mental health services and supports</li> <li>• Practitioner discourse and terminology on pregnancy loss</li> </ul>
Pregnancy loss stigma	<ul style="list-style-type: none"> <li>• Generational differences</li> <li>• Cultural aversion to death and grief discourse</li> <li>• Ceremony</li> <li>• Lack of support for both bereaved parents</li> </ul>
Personal, interpersonal, and informal supports	<ul style="list-style-type: none"> <li>• Relationships</li> <li>• Connection through the lived/living experience of pregnancy loss</li> <li>• Reciprocity</li> <li>• Grieving processes</li> <li>• Artifacts</li> </ul>
Employer supports	<ul style="list-style-type: none"> <li>• Employer policies</li> <li>• Return to work</li> <li>• Choice</li> <li>• Compassionate employers</li> </ul>

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.<sup>51</sup> Similarly, the *Standards for Obstetrical Ultrasound Assessments* published by Perinatal Services BC<sup>50</sup> 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 strategies.<sup>73</sup>

### *Lived/living experiences of miscarriage recovery in BC*

**Demographics.** In total, 27 people participated in this study's semi-structured interviews, including 26 people who carried the pregnancy(ies) and 1 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. In addition, 27% (n=7) also experienced other types of pregnancy/baby loss(es), such as preclinical pregnancy loss,<sup>74</sup> 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) locations.

**Patient experience themes and subthemes.** Table 1 presents the participant experience themes and subthemes. The key themes include health care access; pregnancy loss stigma; personal, interpersonal, and informal supports; and employer supports. The themes and subthemes are outlined in the following subsections, drawing from participants' quotes.

### *Health care access*

**Lack of follow-up care.** 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. As a participant explained, "I honestly felt like they dropped me like I was hot. . .as soon as there was no living baby inside me anymore" (second trimester miscarriage patient H). 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. 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 a participant expressed after struggling with the loss for 6 months on her own, subsequent follow-ups may be required for several months, including past the expected due date of the baby they lost (first trimester miscarriage

patient W). As noted by another participant, this care should be provided alongside translation services for people whose first language is another language than English (recurrent pregnancy loss patient Y). For participants who did receive thorough prenatal and follow-up care, they credited a particular HCP who led with compassionate care values and practices.

**Limited mental health services and supports.** Patients shared about various mental health implications following miscarriage, including prolonged grief, depression, anxiety, trauma, alcohol use, and attempted suicide. As a participant recalled,

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. (First trimester miscarriage patient I)

In addition, some participants experienced shock, anger, and panic attacks. Yet, participants were rarely referred to mental health services by their HCPs. 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 a participant explained, 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 (second trimester miscarriage patient R). Participants also emphasized the importance of having a choice in the mental health services they receive, such as counseling (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 services), or psychologists and psychiatrists depending on the need and preferences of the patient and partner. In addition, some participants highlighted how couples might require support identifying and understanding different grieving styles among couples. 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” (recurrent pregnancy loss and infant loss patient O).

For some, impacts on their mental health continued through to future pregnancies or while they stopped trying to conceive due to recurrent losses and/or infertility. As a 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” (recurrent pregnancy loss patient B). Furthermore, some patients expressed distress when they were denied having their progesterone levels checked

and/or prescribed progesterone after requesting it following recurrent miscarriages, despite its wide usage in the United Kingdom to reduce the risk of recurrent losses.<sup>27,75</sup>

**Practitioner discourse and terminology on pregnancy loss.** What HCPs *say* to patients also had a significant impact. Patients from this study shared how terminologies 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 recalled:

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.

(First trimester miscarriage patient Q)

In addition, general pregnancy loss discourse mattered. 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” (recurrent pregnancy loss patient K). This type of discourse from a HCP suggests the absence of a psychologically safe medical environment—an environment that silences patients from disclosing their health concerns, and potentially, mental health needs.

**Pregnancy loss stigma.** In relation to the current culture surrounding pregnancy loss in Canada, various participants spoke about wanting the “taboo” and “stigma” to change. As a participant noted, “It doesn’t feel like culturally we have enough permission to be honest about how when it happened—when miscarriage happens, how it goes” (recurrent pregnancy loss patient L). 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 long-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.<sup>76,77</sup> Various participants noted this is particularly challenging for men during pregnancy loss. As expressed by a participant, “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” (recurrent pregnancy loss patient C). 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. (Recurrent pregnancy loss patient E)

Moreover, pregnancy loss stigma impacts patients and the other bereaved parent.

*Personal, interpersonal, and informal supports.* 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 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, neighbor, 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. As noted by a participant, “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” (second trimester miscarriage patient R).

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 (and potentially 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 amid systems that commonly did not provide support.

*Employer supports.* 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 recurrent pregnancy loss patient E. Another participant recalled being asked to return to work after 2 days off, before she was ready to go back (recurrent pregnancy loss patient G). An HCP who had a miscarriage 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” (recurrent pregnancy loss patient Y). 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 recurrent pregnancy loss patient L. 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 sooner. There are also some employers that exceed legislated employment standards to support employees after pregnancy loss. As a participant shared:

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. (First trimester miscarriage patient I)

Compassionate employers who provided people with 2–3 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/labor standards legislated for the respective jurisdictions. 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.”<sup>52</sup> 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 (see Table 2). The lack of explicit pregnancy loss language in BC’s and other jurisdictional employment legislation

**Table 2.** Bereavement leave legislation in Canada (at the time of publication).

Jurisdiction	Allocation	Pregnancy loss language
British Columbia <sup>52</sup>	3 days unpaid	No
Alberta <sup>53</sup>	3 days unpaid	Yes
Saskatchewan <sup>54</sup>	5 days unpaid	No
Manitoba <sup>55</sup>	3 days unpaid	No
Ontario <sup>56</sup>	2 days unpaid	No
Quebec <sup>57</sup>	2 days paid + 3 days unpaid for immediate family only, otherwise 1 day unpaid	Yes, but only for 20 + weeks of gestation
New Brunswick <sup>58</sup>	5 days unpaid	No
Nova Scotia <sup>59</sup>	5 days unpaid	No
Prince Edward Island <sup>60</sup>	1 day paid + 2 days unpaid for immediate family only, otherwise 3 days unpaid	Yes
Newfoundland and Labrador <sup>61</sup>	1 day paid leave + 2 days unpaid	No
Nunavut <sup>64</sup>	No bereavement leave policy	N/A
Northwest Territories <sup>62</sup>	3 days unpaid within community; 7 days unpaid if travel is required	No
Yukon <sup>63</sup>	1 week unpaid	No

means employees and employers need to interpret if an unborn child is included in the “family member” definition. 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.<sup>57</sup>

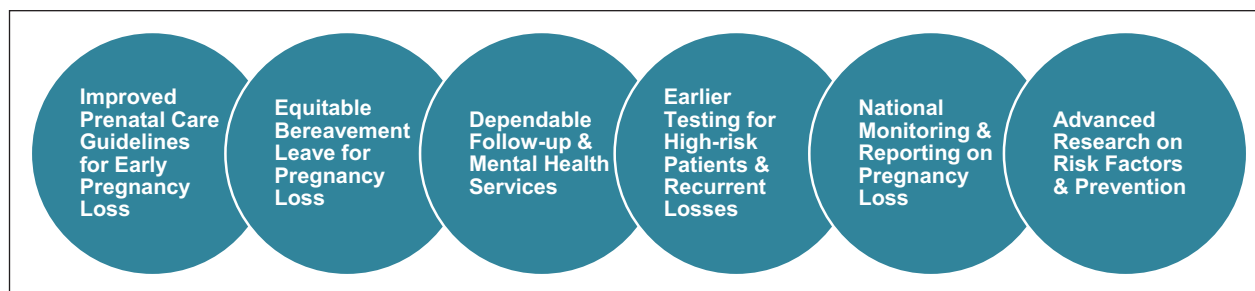
## Discussion

In BC, there are significant gaps in prenatal care guidelines between stillbirth (pregnancy loss after 20 weeks) and miscarriage (before 20 weeks), with guidelines for miscarriage 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; people with miscarriages 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 contributes to existing pregnancy loss stigmas that do 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, mental health screening and supports, and information on optional ceremonial services. In addition, the inclusion of diagnosable risk factors would support dissemination to HCPs, and thus, aid patients during recovery and future reproductive outcomes by knowing, when possible, what happened. Furthermore, using non-gendered language (e.g. person carrying the pregnancy and their partner) in guidelines recognizes sex and gender diversity among patients.

The absence of evaluation and care guidelines for pregnancy losses before 20 weeks begins to explain the lack of consistency in diagnoses and follow-up care for miscarriage discussed in the lived/living experiences subsection of this article. As previously asserted by Dugas and Slane,<sup>78</sup> “Treating patients who experience pregnancy loss requires close coordination between all members of the care team.” This should also include engaging the patient in decisions on initial and subsequent follow-up care. Asking the patient and, if applicable, the other bereaved parent what terminology they would like used while referring to their loss is another way patients and bereaved parents can be engaged in decision-making to support recovery. Furthermore, 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.<sup>3-12</sup> Moreover, follow-up care for miscarriage should include mental health screening for the patient and other bereaved parent, and if needed, navigation support to accessible mental health services. As previously asserted by Tommy’s National Centre for Miscarriage Research<sup>79</sup> and Miller et al.,<sup>80</sup> these findings confirm how the cultural shift related to pregnancy loss needs to support both patients and partners.

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 for earlier testing,<sup>81,82</sup> such as Tommy’s National Centre for Miscarriage Research graded module of care in the United Kingdom.<sup>83,84</sup> 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.<sup>3,85</sup> More research on risk factors for pregnancy loss and prevention is also required. As shown in Figure 1,





**Figure 1.** Improving integrated health care for pregnancy loss in BC and beyond.

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.

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. 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. 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 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 3 days *paid* leave are provided *per* bereavement.<sup>86</sup> While grieving processes generally extend far beyond 3 days,<sup>13</sup> bereavement leave can be combined with paid leave as needed through BC's legislated 5 paid sick days, Canada's employment insurance (EI), and if provided by an employer, extended health leave benefits.

### Strengths and limitations

The patient-oriented methodological approach was a strength of this study, centered on patient experiences. In addition, the findings from the different data sources were triangulated to make health system transformation recommendations. Limitations involved recruiting participants from a rural health authority. 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 rural health regions to further explore barriers to pregnancy loss care in remote and rural geographical 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 patient who carried the pregnancy. Future research could consider explicitly exploring couples' experiences with pregnancy loss.

### Conclusion

Patient experiences of health care access; pregnancy loss stigma; personal, interpersonal, and informal supports; and employer supports were triangulated with policy analysis on prenatal care guidelines and bereavement leave legislation to inform health systems transformation for pregnancy loss care in BC. Recommendations include (a) improved prenatal care guidelines for early pregnancy loss, (b) equitable bereavement leave for pregnancy loss, (c) dependable follow-up and mental health services, (d) earlier testing for high-risk patients and recurrent losses, (e) national monitoring and reporting on pregnancy loss, and (f) advanced research on risk factors and prevention. This research can also serve as a model for other provinces and territories in Canada, and other countries, to evaluate regional and national pregnancy loss care and improve reciprocal research, policy, and health services for pregnancy loss care and prevention.

### Declarations

#### *Ethics approval and consent to participate*

This research study was approved by the Royal Roads University Research Ethics Board (approval record: *Van Tuyl 5/13/2022*). Participants provided written consent; consent was reconfirmed verbally prior to starting the interviews and recorded accordingly.

#### *Consent for publication*

As part of the informed consent process, participants consented for anonymized research findings to be published.

#### *Author contribution(s)*

**Rana Van Tuyl:** Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Resources; Software; Supervision; Validation; Visualization; Writing—original draft; Writing—review and editing.

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### Competing interests

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### Availability of data and materials

The policy research data on prenatal care guidelines and bereavement leave legislation can be made available for basic data sharing by request. Interview and discovery action dialogue data are not available to protect the identities of the participants.

### Note to reader

This article contains lived/living experience(s) information on pregnancy loss, and as such, it may evoke sensitive memories and emotions for people who have experienced loss.

### ORCID iD

Rana Van Tuyl  <https://orcid.org/0000-0003-1750-3117>

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