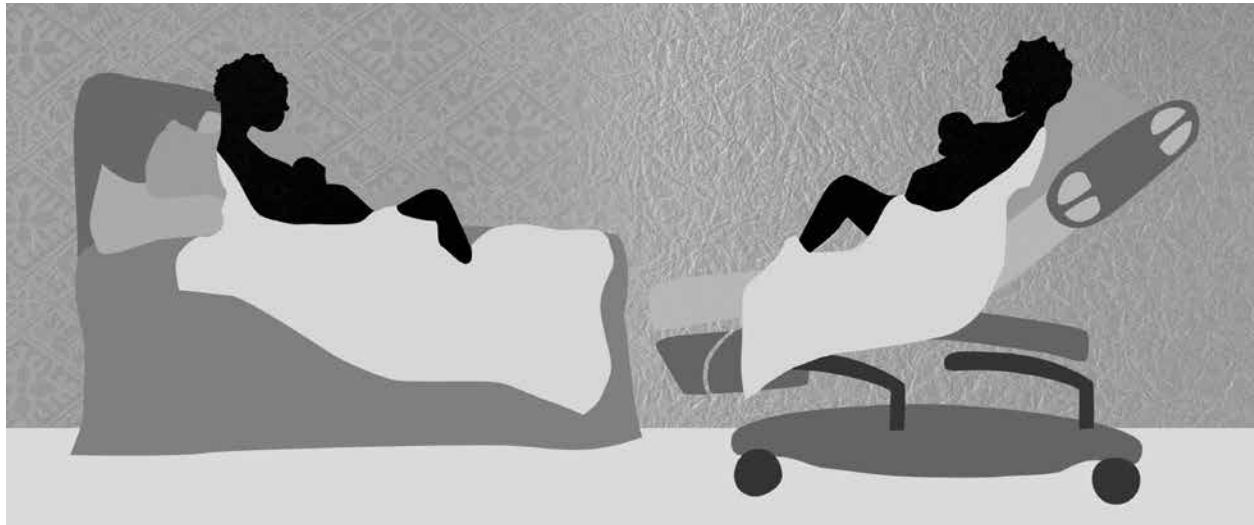




Midwifery Client Experiences of **POSTPARTUM HEMORRHAGE**



While there is abundant literature on the acute clinical management of postpartum hemorrhage (PPH), there is less information available to guide midwives in providing care that meets the emotional needs of clients who experience significant postpartum blood loss, especially with data from a Canadian context. Three major themes can be drawn from existing qualitative literature on experiences of PPH:

- education and support needs of families before, during and after PPH (1–5);
- difficulty initiating chest or breastfeeding (6); and
- emotional and physical sequelae (7–10).

As part of a project to develop informational materials for midwifery clients who have experienced a PPH, the clinical practice guidelines program at the Association of Ontario Midwives (AOM) conducted focus groups and an online survey with midwifery clients and midwives, to explore Ontario midwifery clients' experiences of PPH in Ontario.

This document offers an overview of some of the findings of these activities. We have included quotes from survey and focus group participants that highlight some of the themes listed above, as well as experiences that diverge from the existing qualitative research. While the experiences of our participants do not represent a complete range of experiences and opinions, we hope that the information in this document may help to enhance your understanding of Ontario midwifery clients' experiences of PPH, and may serve to inform and enrich your practice and perspective.

We also want to recognize that the AOM is committed, through our statement on Gender Inclusivity and Human Rights, to reflect and include trans, genderqueer and intersex communities in all aspects of our work. This document refers to gendered language throughout as all survey participants self-identified as women.

We asked: Can you tell us about your PPH experience?

The participants in this project shared a variety of stories that covered a range of experiences of PPH. Most participants felt very well cared for and supported by their midwives throughout their experience. Although research available from a variety of European contexts points to dissatisfaction with the acute and follow-up care of a PPH, the participants we talked to commonly reported feeling confident with their midwives' management of the event and appreciative and grateful for the postpartum care and support they received.

Comments related to satisfaction were dispersed throughout participants' narratives, which covered a range of topics including physical memories and emotional responses. Participants commonly recounted their experience of manual removal of the placenta/clots and bimanual compression (in some cases performed by midwives both in and out of the hospital setting, and in some cases performed by physicians) as extremely painful.

"Unfortunately they were sort of, whatever that is when they're going in and helping all these clots come out, which was a million times more painful than pushing a 10-pound baby out."

"I just remember the pushing on my stomach. I had bruising from it. It was very painful because I didn't have any medication at all or anything. So I remember that. That was a bit traumatic for me. I remember it being equally as painful as my labour."

Others participants recounted feeling embarrassed and uncomfortable with the blood loss.

"PPH is messy and it's unpredictable and you're just sort of sitting in this puddle or lying in a puddle."

"I had a clot that was literally the size of a baseball. It was horrifying, and I had made a

bowel movement and I had to call [someone] to look at it, and it was humiliating."

The transfer to the hospital was typically recounted as difficult and stressful for the five women who had planned home births but ultimately ended up in hospital. Experiences in hospital varied. Some clients described interprofessional tension while others described their sense of positive working relationships between midwives and other hospital staff. Some women were separated from their babies during the management of the PPH, and reported feeling distress in the immediate postpartum.

"I had in my mind what you imagine a home birth to be when you're able to do all the things you want to do—to hold your baby—and here my baby was in a car seat, he wasn't even in my husband's arms. That was a rough start to the bonding process for sure."

"We were separated at birth, which wasn't what I had pictured. So that was a bit—that was hard."

We asked: can you tell us about your physical recovery?

Many of the women described their physical recovery as "exhausting" or "tiring" and taking longer than usual.

"I remember the extreme exhaustion. I remember trying to wash my hair and I couldn't lift my hands up, I just felt so faint and tired."

"It was really exhausting and I was pretty depressed, I didn't have postpartum depression, but being bedridden while having children was really difficult. I didn't leave my room for 10 days, and then when I tried, I would literally walk to the dining room table and then had [sic] to go back to bed, and I had transfusions, so it was really rough for me."

"It knocked me flat. I could not do anything for two weeks. I was shocked at what an

impact it had on my recovery. [It was] just weird to not be able to get your body to do what you wanted it to do. I wasn't even sore. I just couldn't move. It was different than being really tired too. I mean it was, but it's not anything close to being just really tired. It was so beyond that."

Other women did not recall their physical recovery as particularly challenging. These women's experiences are consistent with a multicentre cohort study that did not find evidence for increased fatigue in women with PPH compared to the general population. (9) The physical effect of blood loss was variable in our sample.

"Recovery was fine. Went home the next day, no worries."

"I felt fine. I wasn't experiencing any of the symptoms that come with decreased blood in your body other than I had a headache."

Aside from fatigue, participants also described feeling extreme hunger and unusual cravings.

"Probably one of the weirdest sensations I ever had afterwards was the hunger. I've never been that hungry in my life. I ate so much food. Everything they brought me at the hospital, I was eating it, and it still wasn't enough. I was raiding pantries. I didn't realize that it was because of losing all that blood, I was so hungry."

"I was a vegan and I just ate every meat product possible and loved it."

We asked: can you tell us about your emotional recovery?

The emotional sequelae of PPH cited in the literature includes post traumatic stress disorder (PTSD), feelings of failure as a parent related to relinquishing care of the baby, ongoing nightmares, anxiety and fear, phobia about hospitals, persistent fear of death, sexual avoidance, and interpersonal conflicts. (7,8) The participants in our focus groups experienced some of these issues.

Clients' experience of informed choice in an unfolding crisis

Research conducted in the United Kingdom found that clients and their partners often felt disempowered during their PPH and recovery, and described themselves as passive participants, "with few expectations of involvement in discussions or decisions." (1) This is contrary to what was reported by participants in our focus groups and surveys. Many participants described their midwives engaging them in an ongoing informed choice process during the emergency and into the postpartum period. One client described the ongoing collaborative decision making that went on during her transfer to hospital from a planned home birth: "Anything that was asked or discussed we made sure we brought it back to the midwives and we decided constantly." A high value was placed on this engaged decision-making process by all of the women who described it.

For instance, a few women described feeling guilty and scared that they could not perform activities that they thought they should be able to.

"Emotionally, the guilt of not being there for my child immediately after birth was difficult."

"I feared that I wouldn't be able to look after my baby."

"I don't think I was prepared for how I would feel afterwards. I think I tried to go back to doing the things I thought I should be doing right away and then feeling pretty bad that I couldn't be doing them and not really realizing that you should probably just be in bed."

Anxiety, nightmares and flashbacks were described by women in our group. These feelings sometimes affected women in their subsequent pregnancies, and sometimes lasted long into the postpartum period.

“I think I experienced not severe post traumatic stress but something like that. I would have flashbacks to the pain, mostly the pushing on my stomach. I can still feel that. It hurt and it was a bit traumatic and I didn’t recognize it as trauma... I think I just thought it was normal to have those feeling after birth because it is such a dramatic change. But I think, looking back, I just didn’t realize that it was traumatic. So I’m still dealing with it, I think.”

“For the first 18 months postpartum, I don’t think I fully processed what happened to me. I was functioning on auto-pilot and would be very “matter-of-fact” when discussing my experience. I have since been diagnosed with PTSD from the event, along with severe anxiety. I am high-functioning though, so I didn’t realize how much it affected me. I feel very numb about the event and have trouble recalling exactly what happened.”

“I was worried. I was stressed during the second half of my [second] pregnancy that I was going to have a PPH.”

“I remember anytime I saw an ambulance—I don’t know if you would call it flashbacks—but it just, it was anxiety. I had anxiety from the whole experience, and I didn’t know I was suffering that until that day I was driving and I see an ambulance and it’s just like all that emotion floating back.”

“I was terrified that I was going to bleed to death at some random time. It happened while driving once and it was pouring down my legs. [I] cried hysterically until I got home. [I] was so scared I was going to leave my daughter with no mother.”

Other women did not experience their PPH as traumatic or stressful. This is in line with a multicentre study that showed no increased anxiety in women with PPH compared to the general population. (9)

“I felt fine. It wasn’t traumatic to me other than I want to know why it happened and how, for a second kid, it doesn’t happen.”

We asked: what kind of supports did you turn to during your recovery?

Participants often described positive experiences in their recovery stories, even when their recovery was particularly challenging. Coping strategies like these are rarely discussed in the literature, but provide important insight in the way these women and their families were able to creatively adapt to their unexpected circumstances. Women discussed the benefit of planning ahead of time, relying extensively on support systems, incorporating older children in recovery, and writing out stories of experiences. One study (11) found that writing out birth stories had measurable, positive effects for women suffering from PTSD as a result of childbirth trauma.

“[A couple days] before my second birth I wrote out my story in words, and [it] just flooded out. It was so healing for me to do that, and I wonder if that may have contributed—I think it did contribute—to my peaceful [second] birth. It was just exactly what I would have wanted, it was absolutely that. Sure it was painful, but it was wonderful, and I think I had to do that get it out.”

“We had planned to do a six-week lay-in, so thankfully I didn’t have these grandiose plans of going out the next day with my baby. We stayed in for the full six weeks ... and emotionally I think everything was just fine for us afterwards surprisingly. But I think we really just took the time.”

“My friends were like ‘don’t do anything’ and I was like, ‘OK!’ My mom came and made me meals, we had a calendar at the house, breakfast, lunch and dinner, and friends signed up if they wanted to come and visit. But they had to bring a meal.”

“We had picnics in bed for dinner every night. And, we did a lot of like bedtime activities, like we painted our nails, [my son] painted my nails and we painted his nails and we all had the same colour nails and there was a lot of family time in the bed and [my son] really went with it.”

We asked: did your PPH affect breastfeeding?

Delayed lactogenesis has been cited as a side-effect of PPH (6); however, most of the women we interviewed did not report breastfeeding problems or milk supply issues.

The three survey respondents and one focus group participant who felt their breastfeeding was affected by their PPH cited the separation from baby, overall fatigue associated with PPH recovery, and lack of support for breastfeeding from hospital staff and midwives as sources of this difficulty. One participant expressed gratitude that her midwives didn't discuss the possibility of delayed lactogenesis, and felt that their implicit assumption that breastfeeding would go well for her contributed to her positive experience.

“I missed out on skin-to-skin in the first hour. My husband had it instead. I had a few minutes immediately after birth. My son tried to latch to my partner and gave up by the time he got to me...I feel PPH played a role in my breastfeeding problems.”

“My lack of strength, energy and pain during recovery made breastfeeding effectively a major challenge.”

“We did have some difficulty breastfeeding at first, although I think this was due more to incorrect information that I was receiving from hospital staff and even my midwife. I wish that I had been better supported by my midwife and hospital staff regarding

breastfeeding my son. I was told repeatedly by different people on my care team that I should “expect breastfeeding problems” considering the hemorrhage I had had. [They said] I would definitely have problems. My milk actually came in normally on day three, and I was incredibly engorged and yet I was being encouraged to feed my son formula.”

We asked: in hindsight, what do you wish you'd been offered before or after your PPH?

Focus group participants said they would have liked:

- More information in the prenatal period about potential emergencies including PPH (this point was debated by several participants, because they also recognized the challenge of reviewing all potential emergencies and the possibility that this may result in unnecessary fear).
- A discussion about the benefits and risks of blood transfusions and information about whether or not a blood transfusion was an option for their recovery.
- More emotional support in the immediate postpartum.
- More vigilant screening to differentiate between symptoms of anemia and symptoms of postpartum depression/anxiety/PTSD.
- Information about typical feelings of fatigue and exhaustion (symptoms of anemia) in order to set realistic expectations for recovery.
- More breastfeeding support/encouragement with less focus on an expectation of delayed lactogenesis.
- The ability to contact their midwives to ask questions or debrief after being discharged from midwifery care since a “delayed reaction” to the PPH was reported by many participants.

We asked: what components of midwifery care did you enjoy or appreciate?

Focus group participants said they appreciated:

- Keeping the baby skin-to-skin during the management of PPH.
- Continuity of midwifery care during ambulance transfers (midwives riding in the ambulance/starting IVs rather than emergency medical services), and in the hospital when care was transferred to another health-care provider.
- Midwives' explanations and support for an informed choice process even during an emergency.
- Midwives' explanations to family members (partners, children, siblings) and inclusion of clients and family members in decision-making during an emergency situation.
- Midwives' calm and skilled management of emergency situations.
- The ability to debrief in the postpartum period and frequent check-ins from midwives.

"I think one of the reasons why I had a really good experience with it was that I had a very high level of trust with my midwives. I just really trusted them. They either made decisions they needed to make quickly or involved me in the decisions whenever they could. I didn't have to worry about something going wrong because I knew if something went wrong they would handle it and I would be involved in handling it as well."

Please visit ontariomidwives.ca/pph for additional client-directed resources on this topic.

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