

**UNEXPECTED TERMINATION OF PREGNANCY FOR FETAL ANOMALY: A
PATIENT RESOURCE MANUAL**

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Abstract

Background: Registered nurses (RNs) working in a Women's Health Inpatient Unit (WHIU) encounter approximately 30 miscarriages and stillbirths per year, including the need for unexpected termination of pregnancies due to fetal anomaly. Many patients lack education or preparation for labour stimulation, leading to emotional distress. A patient resource manual (PRM) can help educate and assist to alleviate some distress for these patients and families.

Purpose: To develop a resource for patients and families undergoing a planned termination of pregnancy for fetal anomaly. **Methods:** I completed a literature review, an environmental scan of local and regional facilities that offer planned pregnancy terminations, and consultations with local key stakeholders. **Results:** Findings from the literature review, consultations, and environment scan supported the need for an educational resource about the termination of pregnancy for patients and families. The most appropriate mode of delivery is a PRM in printable booklet form, and the content should include expectations with admission to the inpatient unit, the step-for-step labour process with vaginal delivery, and expectations for medication administration. **Conclusion:** The creation of the PRM, a patient guide to treatment for termination of pregnancy, is expected to enhance the knowledge of patients and families before beginning the termination process. It is further anticipated that this PRM will ease patient suffering and improve coping during the termination and subsequent bereavement process, leading to fewer adverse health outcomes for patients and families.

Keywords: termination of pregnancy, fetal anomaly, education, resource

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Introduction

“There is no footprint too small to leave an imprint on this world” (Author unknown). Some describe perinatal loss as the most traumatic loss that a person can experience, explained as more complex than the loss of a parent or spouse (Hendson & Davies, 2018; Kalanlar, 2018; Rent et al., 2023; Tseng et al., 2014; Vivekananda et al., 2023), as the hopes and dreams for the future are also lost (Gundry et al., 2023; Henderson & Davies, 2018; Power et al., 2022; Robinson and Robinson, Esq., 2022). *Perinatal loss* is an umbrella of terms that includes miscarriage, stillbirth, neonatal death (Evans et al., 2022; Roberts et al., 2021), and termination of pregnancy due to fetal anomaly (Lu, 2022), and is known to cause deep, traumatic grief (Arrington & Fairchild, 2022; Power et al., 2022; Roberts et al., 2021; Smith et al., 2020b; Trudeau et al., 2022).

I have drawn on the theoretical lens of relational inquiry to understand the experience of perinatal loss more deeply and fully. Following the relational inquiry approach, I focused on what is essential for patients and families to receive as enhanced support following perinatal loss. I collaborated with other healthcare team members to integrate this knowledge into practice by developing the PRM. Compassion is a relational, intentional, and ethical response to recognizing, understanding, and trying to ease patient suffering (Younas, 2020). I have identified a gap in knowledge provided to patients and families undergoing a termination of pregnancy, which may lead to patient suffering. By identifying this gap in care, I am attempting to reduce the impact of suffering by informing patients and families of the steps in the termination process. Inquiry-based nursing practice includes being in the in-between relational space of knowing and not knowing, being curious, looking for significance, and examining the interrelationship between elements (Doane & Varcoe, 2015). By engaging in broad and specific inquiries of perinatal loss,

I better understand the patient's description of the suffering and am aware of available support. At the same time, I located and enhanced the support provided to the sufferers during the perinatal loss experience by completing modifications of a resource from the Izaak Walton Killam (IWK) Hospital (2021).

Perinatal loss is often considered a loss that is silent because of the isolating emotions it creates (Ayebare et al., 2021; Kelley & Trinidad, 2012; Limbo & Kobler, 2010; Salgado et al., 2020; Tseng et al., 2014; Vivekananda et al., 2023). Ayebare et al. (2021) and Tseng et al. (2014) examined how, during an early miscarriage, because there may be little or no physical fetus to grieve, it leaves patients and families to mourn the possible relationship as opposed to tangible memories which are necessary for long term grieving. This can also be true for patients and families who chose at the height of the chaos not to see or hold their terminated fetus after delivery. The Public Health Agency of Canada (PHAC) describes genetic defects as the most common reason for loss of a pregnancy (PHAC, 2022). When a fetus is found to have an anomaly, parents often go through stages of grief like the experience of those who have lost a child (Power et al., 2022). Parents voice mourning the loss of the “normal” healthy baby they envisioned and dreamed of for the future (PHAC, 2022; Power et al., 2022). Congenital anomalies are usually structural or functional, mostly identified prenatally through routine anatomy scans; however, diagnosis at birth or later in infancy may also occur (Hendson & Davies, 2018; PHAC, 2022). This is overwhelming for families as they face the decision of termination of pregnancy because of a malformation or defect (Hendson & Davies, 2018; Lu, 2022; PHAC, 2022; Power et al., 2022). In my role as a RN, I have often seen confusion and despair by those who arrive at the WHIU for planned termination.

When some patients and families arrive for admission for pregnancy termination, they often arrive unsure of the steps to come, unsure of the physical labour and vaginal delivery they must undergo, some even expecting just a quick procedure to occur. When patients and families arrive without advanced knowledge of the termination procedure, there is room for unnecessary patient suffering. With access to enhanced support during a loss, there is less risk of developing mental disorders such as anxiety, post-traumatic stress disorder (PTSD), and depression (Abdel et al., 2021; Al-Gamal et al., 2021; Rent et al., 2023). Evidence from the literature reinforces the positive impact on grief, depression, and anxiety when written information from a support program is provided (Abdel et al., 2021; Alghamdi & Jarrett, 2016; Ayebare et al., 2021; Garcia et al., 2023; Kalanlar, 2018; Kelley & Trinidad, 2012; Meyer et al., 2016; Power et al., 2022; Rent et al., 2023; Salgado et al., 2020; Tseng et al., 2014). Indeed, Abdel et al. (2021) and Rent et al. (2023) found that when a structured program is offered to assist with bereavement in the NICU, the enhanced support given to prepare patients and families lessens the effect of mental health consequences during and after the loss experience.

Support is needed for patients and family members to prepare for and handle the emotional turmoil of perinatal loss *before* beginning the termination process (Power et al., 2022). Shock, denial, and complex emotional distress are often experienced, as parents decide whether to continue their pregnancy or undergo a medical termination. Because of the later gestation of diagnosis, admission to the hospital is required for delivery of the baby for congenital anomalies. Ultimately, my aim with this project was to improve outcomes for patients and families undergoing unexpected, planned terminations and facilitate nurses' ability to provide high-quality care to these patients through pre-termination education and support.

The overarching goal of this project was to inform patients and families what to expect when receiving a medical termination of pregnancy for fetal anomaly. I plan to introduce a patient resource manual (PRM) to patients and families during the diagnosis of fetal anomaly before admission to the hospital to begin the termination process. This pre-termination education approach will assist the nurses on a women's health inpatient unit (WHIU) to provide improved nursing care to these patients and families. I expect that, eventually, this resource may be implemented through other clinical areas in the healthcare facility, such as the emergency department (ER) or Janeway Case room (CR), as these two clinical areas may also receive a patient during the diagnosis of fetal anomaly. Eventually, my hope is that this PRM is implemented in other areas of Newfoundland and Labrador (NL) Health Services (NLHS) that may receive and care for this population of patients. The nurse educator for the WHIU and CR can introduce the PRM to graduate and/or newly hired registered nurses (RNs) during orientation within NLHS programs. In summary, the purpose of my practicum project was to create a PRM to educate and provide support for patients and families about the termination process, including vaginal delivery before hospital admission as well as include the available resources and support within NLHS. For this practicum project, I outlined the following key objectives:

Objectives

1. Explore factors affecting the identified patient education gap before beginning the termination process.
2. Examine local pertinent concerns surrounding the bereavement process in consultation with key stakeholders.
3. Develop and conduct an environmental scan to inform strategic planning and decision-making for my PRM by exploring resources available in other jurisdictions.

4. Demonstrate advanced nursing practice competencies (CNA, 2019) such as improving quality and developing practice through leadership and a collaborative approach.

In the following sections, I describe the methods I used to achieve these objectives.

Overview of Methods

I used three methods of data collection to develop this resource: a literature review, consultations with local key stakeholders, and an environmental scan of other healthcare facilities in both NL and selected locations in Canada. First, I searched the available literature to review, analyze and synthesize relevant research. The purpose of the literature review was to obtain relevant, timely research on my chosen topic of pregnancy termination, especially a review of the benefits of education and support before the termination process. Next, I completed consultations with local key stakeholders of the WHIU while simultaneously gathering data from other healthcare facilities via an environmental scan. The purpose of consultations was to capture local perceptions of the need of the PRM, as well as proposed content and mode of delivery. Valuable information was obtained by listening to local key stakeholders' feedback and concerns and was used to assist with formulating the content for the PRM as well as mode of delivery. Through the environmental scan, I aimed to explore the use of other educational resources about planned terminations from healthcare facilities locally in Newfoundland and Labrador, as well as two locations in Canada. The data collected during the environmental scan guided the design of the patient resource manual, which was uniquely custom-made to match the contextually relevant needs of the local WHIU.

Summary of the Literature Review

In the literature review, I explored both qualitative and quantitative literature on pregnancy loss in general, as well as later gestation pregnancy loss. I appraised the literature using the Public Health Agency of Canada (PHAC) Critical Appraisal Toolkit (2014) for quantitative research and the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for qualitative research. My literature search also included termination of pregnancy and existing support; however, there was minimal research available surrounding unexpected, planned pregnancy termination. As such, most of the literature reviewed was about pregnancy loss in general.

I explored the prevalence of perinatal loss and the impact of both the loss itself and the scarce amount of available literature surrounding the bereavement process after unexpected terminations of pregnancy. In Canada, perinatal loss varies from 7.5 to 8.1 per 1000 births (PHAC, 2022). Despite this prevalence, I found minimal research surrounding advised/planned termination of pregnancy. Perinatal loss is an important health concern and is documented as so in many scholarly published articles and research studies as the impact can be harming to not only the patient but the family unit because dreams and hopes for the future are also lost (PHAC, 2022; Power et al., 2022).

Language used by healthcare providers can lead to miscommunication surrounding expectations, such as the number of terms used to describe perinatal loss (Smith et al., 2020a). The terminology used by healthcare providers or educational material can lead to confusion during the termination and delivery process; for example, using the term miscarriage to describe the vaginal delivery of 20-week gestation baby (Smith et al., 2020a). Additionally, parents feel the lack of a publicly mourned loss, or the socially accepted bereavement process leads to intense

feelings of grief, sorrow, emptiness, and helplessness from the lack of validation (Smith et al., 2020a). Complicating this notion of "silent loss" is the lack of formal documentation, such as live birth and death certificates provided to patients and families during the termination process (Fairchild & Arrington, 2022; Salgado et al., 2020; Tseng et al., 2014). This lack of documentation was also identified as a key determinant of distress during the consultations with local key stakeholders.

The collection of fingerprints, handprints, and holding of the fetus post-delivery assists with creating essential memories for the long-term grieving process and should be offered with preparation to all families (Blood & Cacciatore, 2014; Kalanlar, 2018; Smith et al., 2020a). Making memories during the immediate post-delivery period is necessary because of the quick deterioration of the condition of the fetus after delivery at early gestations and this should be explained to patients and families before delivery (Blood & Cacciatore, 2014; Kalanlar, 2018; Smith et al., 2020a).

Anxiety, depression, panic disorder, and post-traumatic stress disorder (PTSD) may be linked to the widespread disregard for the needs of parents facing perinatal loss (Cambonie et al., 2023; Evans et al., 2022; Fairchild & Arrington, 2022; Garcia et al., 2020; Gundry et al., 2023; Roberts et al., 2021; Smith et al., 2020a; Smith et al., 2020b). When patients and families have access to enhanced support when facing their loss, the impact of the loss is experienced to a lesser extent (Abdel Razeq et al., 2021; Lu, 2022).

As a result of my findings from the literature review, I determined that the PRM must include explanations of terminology including the term and classification of miscarriage, provide official documentation explanation, as well as explanations of appearance of the baby due to their deconditioning at lower gestations, and the importance of seeing and holding the baby for

long term grieving. Please see Appendix A for the literature review and Appendix B for the literature summary tables. Along with the literature review, I gathered information for the content and mode of delivery for the PRM through consultations with local key stakeholders and an environmental scan.

Summary of Consultations and Environmental Scan

Consultations with key local stakeholders are vital because for a change in practice to be effectively implemented by a group of people, the group of people need to recognize the idea as transformational (LaMorte, 2022). I identified the local key stakeholders as the WHIU psychologist, the WHIU social worker, two senior registered nurses (RNs), two novice RNs, and one patient with a history of perinatal loss. These individuals were identified as key stakeholders because these members are a part of the bereavement consultation process as a collaborative team approach to provide optimal supportive care and therefore their feedback is vital for the PRM construction. For this project, I identified senior nurses as having five years or more experience with bereaved patients and novice nurses as having less than two years' experience. Informal face-to-face consultations were arranged through an invitation email with all members except the WHIU social worker, as this position was vacant during the time of my consultations. I did, however, obtain rich, thick data from the other consultees and I plan to consult with the social worker prior to implementation of the PRM, as I will discuss later in this report. For this report, I will refer to individuals consulted as "consultees". I asked the consultees questions about current information received before beginning the termination process, if a PRM would be helpful if provided to clients who must undergo an unexpected termination of pregnancy, when they think a manual should be provided, and appropriate content for the manual. Consultees agree that a PRM could benefit patients and families beginning the termination process.

Precisely, they identified that a knowledge gap exists before the termination process. This was also echoed in the literature review, and Roberts et al. (2021) identified that when patients and families do not receive enough education surrounding the steps to come throughout the labour process, this may lead to an unnecessary increase in patient suffering. To develop an effective PRM that will be utilized, consultations with local key holders were vital to determine how consistent the idea for a PRM is with the would-be adopters' values, experiences, and needs (LaMorte, 2022).

Of high importance in the consultation phase, I consulted with an individual who had previously experienced an unexpected, planned pregnancy termination. This individual also expressed that education before beginning the termination process is ideal. As this is a resource for patients and families, the input of patients and families is essential. Moving forward for implementation of the PRM, it will be integral to seek the ongoing input of patients and families prior to, during, as well as post-implementation to ensure the resource meets their needs.

Throughout the consultations, I took handwritten notes directly onto a printed copy of my interview guide and then transcribed the notes into a Microsoft document. This transcription occurred as soon as possible to ensure an accurate recollection of the face-to-face interviews as soon as possible (Phillippi & Lauderdale, 2017). Additionally, I reviewed the notes to familiarize myself with the information and refresh my recollection to update any missing information.

I used Bengtsson's qualitative content analysis method (Bengtsson, 2016) to explore the data from the consultations. I familiarized myself with data by reviewing each document several times. Using this method, I considered the data and formed conceptualizations in four main stages: decontextualization, recontextualization, categorization, and the assembling of similar themes/groupings (Bengtsson, 2016). I pooled the data into categories and developed final

themes into separate tables which can be seen in Appendix C. Using content analysis to examine social phenomena is non-invasive, instead of stimulating social experiences to collect questionnaire feedback (Paradis et al., 2016). As an example of using this content analysis method, the first theme is that *more information improves understanding*. By providing more information, patients understand what will happen during the termination process. The literature reinforces the positive impact on grief, depression, and anxiety when written information is provided by a support program (Abdel et al., 2021; Alghamdi & Jarrett, 2016; Ayebare et al., 2021; Garcia et al., 2023; Kalanlar, 2018; Kelley & Trinidad, 2012; Meyer et al., 2016; Power et al., 2022; Rent et al., 2023; Salgado et al., 2020; Tseng et al., 2014). In the study by Gundry et al. (2023), they report 78% of participants voiced appreciation for written information from the support program. The second theme is *preparation before is best* and by informing patient and families before beginning the termination process will allow for the processing of information, supporting similar findings in the literature. Gundry et al. (2023) determined that a newsletter offered support and interaction for members of the program in which they were analyzing. The third theme is *mode of delivery: web is best*; web-based was determined to be a favorable mode of delivery to allow for flexibility and delivery of services in rural NL. Similarly in the literature, web-based interventions offer flexible mental health support, addressing the barriers to care, such as social distancing during the pandemic (Hung et al., 2023). The fourth theme is that *information in a step for step process is a must*. As such, providing education to patients in a step for step process of medication administration as well as the labour process is a necessary for the PRM. The fifth theme is *which medical terminology is best? Is it a miscarriage or is it not?* Through consultations the term miscarriage was identified as not adequately depicting vaginal delivery even though technically speaking most terminations delivered are considered a

miscarriage because of their size. Similarly in the literature, Smith et al. (2020a) determined the language used by healthcare providers can lead to miscommunication surrounding expectations with most participants indicating the term miscarriage not associating with giving birth.

For the environmental scan, I explored four rural sites within of NLHS, as well as the IWK, the Hospital for SickKids (SickKids), and the Athena Health Centre (AHC) for patient resources regarding planned terminations. I found that other sites within NLHS do not typically perform termination of pregnancies for fetal anomaly and patients are often transferred to the tertiary centre for treatment, therefore no additional data was collected. I attempted on two occasions to connect with the grief support coordinator, Pediatric Advanced Care Team (PACT), and Pathways Grief Support Program for SickKids Research Institute in Toronto, Ontario regarding their resources surrounding loss of a child. However, I did not receive a response to my email. I contacted the bereavement coordinator at the IWK, and they shared various patient guides and resources for pregnancy termination and management of grief for perinatal loss. Based on data from the consultations, I was able to adapt these shared resources to be contextually relevant to the WHIU.

I used a business-based approach taken by Praxie (2022) to organize the information from the environmental scan. Praxie (2022) categorizes information on a topic within political, economic, social, technological, and patient focus themes. This method promoted grouping information into political factors impacting the PRM, economic factors related to the financial constraints for bereavement support, social factors relating to patients and families and perinatal loss, with technological factors and resources for perinatal loss support. Lastly, Praxie (2022) describes patient-related factors such as patients' expectations, needs, and wishes. Using the approach Praxie (2022) for the environmental scan, I organized the information received from

rural NLHS, the AHC, SickKids, and IWK based on political, economic, social, technological, or patient influence. I kept this information in a password-protected Microsoft Word document on a password-protected computer.

Examples of political factors are patients and families outside the metro region of St. John's, NL, who must travel to the WHIU for termination of pregnancy. For example, a patient from St. Anthony, NL must take time off work and potentially lose income to travel, with their spouse who could also potentially lose income from time away from work. Economic factors such as when leaving rural NL for termination adds economic stress of accommodations and travel expenses on top of the already traumatic experience, as well a medication is often given in the community 24 hours before admission and may be expensive depending on insurance coverage. Technological factors include the potential development of a web-based patient resource that can be accessed province wide. Alongside the booklet form, a web-based resource can reach all residents of NL no matter the geographical location in which the patient and family requiring termination resides. Information regarding patient preferences and expectations were categorized in the patient focus theme. Information including the process of misoprostol tablet insertion and what to expect with administration was included in this category.

The data from the consultations and environmental scan have enabled me to create a resource that meets the exclusive educational needs of patients and families facing termination for fetal anomaly on the WHIU. A copy of the environmental scan and consultation report can be found in Appendix C. In the next section, I will provide a summary of the PRM.

Summary of the Resource

Based on findings from the literature review, consultations, and environmental scan, this PRM is comprised of three parts: 1) before admission to hospital, 2) during admission to hospital, and 3) after discharge expectations and supports.

Section One: Before Admission

The first section of the PRM includes all information before admission to hospital divided into five subsections: i) receiving the diagnosis ii) reading support from resolve through sharing: mending a broken heart, iii) information on taking Mifepristone including what to expect at home after taking Mifepristone (Mifeprex®) and iv) where to go for admission. Each subsection is organized in the table of contents for easy navigation and preference of easily selected information to read.

This section is important because in the consultations I found that explanations of medication administration and what to expect regarding side effects and outcomes was desired. Additionally, not every patient and family will want to know every detail of what is to come at a given time. By dividing the resource into three sections with subsection topics, patients and families can easily navigate the PRM to read the desired information at their choice. The stress of patients and families facing pregnancy termination is caused by the uncertainty and unknown surrounding loss and delivery (Evans et al., 2022). Therefore, I aim to educate patients and families with my PRM which includes reading support from the Resolve Through Learning program providing loss support (Gundersen Health System, 2023).

Section Two: During Admission

The second section of the PRM includes information about what to expect during hospital admission and has eight subsections including: i) what happens after you are placed in your

patient room ii) starting the stimulation of labour iii) pain management, iv) preparing for vaginal delivery v) medical examination of the baby vi) burial/funeral arrangements vii) what to expect during delivery and viii) what is a D & C procedure if it is required. Part two is organized into numbered topics for easy navigation.

These topics are crucial to include because I found from the consultations and literature review that patients and families voice shock during the termination process, with rapidly unfolding events leading to delayed processing (Vivekananda et al., 2023) and declining to see or holding the baby (Kalanlar, 2018). Even though concrete images and memories are needed for long-term grieving, many patients and families do not consider memorial photography during the crisis and decline the invitation (Vivekananda et al., 2023). Through consultations, the hope is with the PRM provided to patients and families with the choice up-front before admission to hospital will allow the patient and family time to choose whether to see their baby or have photographs taken (Kalanlar, 2018; Vivekananda et al., 2023) and hopefully improve long-term grieving.

Section Three: After Discharge

The final section includes any information for after discharge with eight subsections including: i) discharge instructions ii) adjusting to the loss of your baby iii) management of breastmilk after the loss of your baby iv) hand expression to facilitate decreasing milk production and other comfort measures to relieve pressure v) the memorial event of A Walk to Remember, St. John's vii) after discharge contacts and connection routes to additional supports.

I included each of these sections because of consultations, environmental scan findings, and literature support. I noted that managing breastmilk and hand expression to facilitate decreasing milk production was important through consultation feedback and was also identified

as important discharge teaching material by the IWK (IWK, 2021). Through consultation feedback details surrounding the memorial event, A Walk to Remember was essential to be included. Bereavement programs incorporating a variety of sections that enable bereaved parents to connect to varying support routes, information about grief support groups, and memorial events are important in coping with perinatal loss (Gundry et al., 2023).

The PRM was constructed in booklet form with the long-term goal of also becoming a web-based resource. Web-based resources lessen the impact of grief by offering flexible support, available when needed by patients and families to review on their own time while providing quick access to many services and linking supports efficiently (Hung et al., 2023). As well, there are many unique family dynamics and having the resource web-based can allow for as many family members to read the resource as desired by the patient and family unit. Web-based interventions offer mental health support as a flexible solution to address barriers to care, such as social distancing during the pandemic (Hung et al., 2023). A website is also a cost-effective intervention to improve quality of life and psychological well-being of the identified population by lessening print shop costs and manpower resources needed for booklet construction.

However, with implementation in mind, booklet form is ideal for this moment in time. The manual can be provided to patients and families during their appointment for diagnosis. As well, the booklet can also be provided to new graduate nurses and newly hired nurses to the area to assist with the education for providing patient care to a family experiencing a loss due to termination. For these reasons, I have determined that, given the scope of this project, the booklet will be a hard copy with future implementation plans to also include an online version that is easily accessible from anywhere in the province.

Implementation Plan

Prior to implementation it is imperative to consult with the social worker once the vacancy is filled for feedback regarding the resource, to ascertain if anything else should be added, or clarify of existing PRM information. Furthermore, it is also integral to seek input from individuals who have experienced planned terminations, to determine if there is information that could be added and/or edited in the PRM. For evaluation of the PRM, I plan to conduct a follow-up survey administered to patients and families during their checkup medical appointment with the doctor usually six weeks postpartum. On discharge is an option, but sensitively is needed to not overwhelm the patient and family with more information and questioning in the immediate postpartum period.

I will present this PRM to management of the WHIU and Maternal Fetal Assessment Unit (MFAU). The MFAU is where most patients and families receive the diagnosis of a fetal anomaly, and ideally where patients and families will receive the PRM before admission to hospital is required. The WHIU manager has agreed to implement the PRM to the target population as soon as the PRM is fully completed.

With future/long-term implementation in mind, the PRM will ideally be expanded to include the patients who receive a diagnosis in the emergency room (ER) of a fetal anomaly before admission to the WHIU, as well as later gestation terminations which require admission to the birthing suite. This will be after implementation in the WHIU.

Ideally, this PRM would also be provided during orientation sessions for the WHIU. The PRM would be a valuable learning tool for new graduate nurses or newly hired nurses to the WHIU, teaching this population too on what to expect during the stimulation of labour for fetal

anomaly. This is not a common concept within the nursing school curriculum and new graduates typically arrive to the WHIU without any bereavement experience for perinatal loss.

By developing my PRM, I have demonstrated Advanced Nursing Practice (ANP) competencies, and the following section will outline those competencies.

Discussion of Advanced Nursing Practice (ANP) Competencies

The development of my practicum project allowed for the achievement of ANP competencies as articulated by the Canadian Nurses Association (CNA) (2019). Core competencies for the Advanced Practice Nurse (APN) are based on an appropriate depth, breadth, and range of nursing knowledge, theory, and research enhanced by clinical experience (CNA, 2019). Throughout this practicum project, I have met the competencies of *research, leadership, collaboration, and* am continuing to meet *health system optimization*, as described by the CNA (2019).

Research Utilization

APNs are devoted to generating, synthesizing, critiquing, and applying research evidence (CNA, 2019). I exhibited this competency by completing a literature review with a critical analysis of research literature. I also collected, analyzed, and synthesized data from the environmental scan and consultations. I am dedicated to practicing evidence-based nursing through critical analysis and synthesis of literature and assisting with developing research skills (CNA, 2019) by developing a PRM based on evidenced-informed, contextually relevant findings.

Leadership

According to CNA (2019), APNs are leaders in their organizations and communities. APNs are agents of change, consistently seeking effective new ways to practice and improve

care. I have met the leadership competency by considering relational inquiry and developing my PRM. To practice relational inquiry as a leader, I facilitated active repositioning of the current practice to achieve client-centred care by collaboratively developing a PRM that included patient perspective. I have represented myself as a leader within my organization by identifying a knowledge gap within our population of patients and striving to develop a PRM to service that need. During this practicum project, I assessed resources and programs in my organization and the community to create a PRM to address the complex issue of the unexpected termination of pregnancy on the WHIU (CNA, 2019).

Collaboration

APNs are expected to consult and collaborate with colleagues across sectors and at the organizational, provincial, national, and international levels (CNA, 2019). I met the competency of collaboration by consulting with members of the WHIU and contacting outside facilities through the environmental scan, both locally and nationally. As a future APN, I have responded to my consultations, environmental scan, and literature review to develop a needed resource.

Optimizing Health Systems

APNs support the operational functioning of health systems through advocacy, promoting advanced client care, and assisting with unbiased, client-centered health care (CNA, 2019). I am meeting this competency of optimizing health systems by promoting client-focused care with integrated evidence and research and contributing to a successful health system with better-quality delivery of service (CNA, 2019). Through the development of the PRM, I have contributed to an effective health system because my goal is to enhance high-quality nursing care, and subsequently, better outcomes for patients and families experiencing unexpected, planned termination for fetal anomaly.

Next Steps

As previously mentioned, before moving forward with implementation, collaboration with the WHIU social work is essential. Next, I will send my PRM to management of the WHIU, as well as the nurse and patient consultees for further refining of the content. I will also seek feedback from the nurse educator of the WHIU program for implementation of the resource into orientation curriculum. Additionally, if the PRM is implemented, I plan to explore the development and implementation in a short survey for patients and families during their six-week check-up appointment to assess the possible benefits and areas for improvement of the resource. As well, a survey will be provided to RNs of the WHIU to capture whether the nurses of the WHIU believed the PRM improved the care provided to these patients and families, as well as any barriers or facilitators to implementation, and the nurse's knowledge uptake.

Conclusion

Based on data from the literature review, consultations, and environmental scan, it is unmistakable that patients and families need enhanced support during perinatal loss. The goal of the PRM is to ensure that patients and families are provided with information and preparation for the termination process before admission to the hospital. The PRM can assist to decrease some of the adverse sequelae of unexpected, planned termination. The goal of the PRM is that when patients and families arrive at the WHIU for termination with the knowledge and education of the steps to come, they will feel more supported through the process. This, in turn, will hopefully facilitate their coping and decrease the risks of anxiety, and depression, or other mental health concerns post-termination. Ultimately, my aim is to provide enhanced support to patients and families experiencing unexpected, planned terminations and the nurses who support them, improving outcomes for all involved.

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Appendix A: Literature Review

Perinatal loss is an umbrella of terms that includes miscarriage, stillbirth, neonatal death (Evans et al., 2022; Roberts et al., 2021), and termination of pregnancy due to fetal anomaly (Lu, 2022), and causes deep, traumatic grief (Arrington & Fairchild, 2022; Power et al., 2022; Roberts et al., 2021; Smith et al., 2020b; Trudeau et al., 2022). For many women, the experience of perinatal loss at any gestation can affect their well-being by the bereavement process (Alghamdi & Jarrett, 2016). Experiencing perinatal loss puts the bereaved at a higher risk of experiencing emotional distress, psychiatric symptoms, and mental illness (Vivekananda et al., 2023). Many families do not get to develop memories or form a relationship with the baby when suffering a perinatal loss. Because of this, the invisibility of perinatal loss can lead to bereaved parents experiencing alienated grief, especially if their loss cannot be visibly mourned for cultural reasons or early gestations (Vivekananda et al., 2023). Historically, healthcare practices inhibited parents from seeing and holding their stillborn babies. Past recommendations of healthcare practices encouraged women and families to quickly forget their loss (Blood & Cacciatore, 2014; Evans et al., 2022; Garcia et al., 2020; Hendson & Davies, 2018; Meyer et al., 2016; Smith et al., 2020a; Smith et al., 2020b). When women and families have access to enhanced support following a loss, there is less risk of developing mental disorders (Abdel et al., 2021; Al-Gamal et al., 2021; Rent et al., 2023). A review of the literature on perinatal loss and the bereavement process highlights the importance of resources and support provided to women and families after perinatal loss.

Overview

Perinatal loss is an important health concern. In this literature review, I will present the prevalence of perinatal loss and explore the impact of scarce literature surrounding the bereavement process after unexpected terminations of pregnancy, therefore identifying a gap in

our knowledge. This literature review is a component of my practicum project: to develop a patient resource manual (PRM) for women and families experiencing termination of pregnancy due to a fetal anomaly. Specifically, through a review of literature, I aim to explore nursing practice and patient outcomes after suffering a perinatal loss. I searched the following databases: the Health Sciences Library, CINAHL, Google Scholar and PubMed. Literature Summary Tables are found in Appendix A. I searched the terms “termination of pregnancy OR abortion OR terminate a pregnancy,” “nursing,” “nursing education,” “bereavement or grief or loss or mourning or death,” “stillbirth, miscarriage” and “patient resource manual” for literature retrieval. I critically appraised the literature using the PHAC Critical Appraisal Toolkit (2014) and the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research (Lockwood et al., 2015).

In the following section, I will discuss the theoretical lens used to guide my literature review. This will be followed by a discussion of bereavement and perinatal loss, including subsequent health outcomes. Next, I will discuss professional bereavement training, and finally, I will provide an overview of bereavement resource literature and the impact of providing enhanced support following perinatal loss.

Theoretical Lens

To understand the perinatal loss experience more deeply and fully, I have adopted the theoretical lens of relational inquiry. Following the relational inquiry approach, I will focus the support needs for women and families following perinatal loss. I will collaborate with other healthcare team members to integrate this knowledge into practice by developing my PRM. The goal of the relational inquiry approach is to accomplish a deeper understanding of patient suffering using compassion, therapeutic communication, and relationship building through the

assembly of trusting relationships (Younas, 2020). Compassion is a relational, intentional, and ethical response to recognizing, understanding, and trying to ease patient suffering (Younas, 2020). I have identified a gap in knowledge with respect to education provided to women and families undergoing a termination of pregnancy. This knowledge gap may lead to increased patient suffering. By identifying this gap and completing this project, I am attempting to reduce suffering by informing women and families of the steps in the termination process. Inquiry-based nursing practice includes being in the in-between relational space of knowing and not knowing, being curious, looking for significance, and examining the interrelationship between elements (Doane & Varcoe, 2015). By engaging in broad and specific inquiries of perinatal loss, I can better understand the patient's description of the suffering, become inquisitive about available support while looking for significance and enhance the support provided to the sufferers during the perinatal loss experience (Doane & Varcoe 2015).

As per Younas (2020), to engage in relational inquiry, I must focus on the relationships and real-time consequences of perinatal loss and critically analyze the experience, situational perspectives, and available knowledge to assist with my PRM development. By adopting the philosophies of hermeneutic phenomenology, critical theory and pragmatism, the relational inquiry approach assists with my analysis of the social and cultural factors of perinatal loss (Younas, 2020). This allows me to question my prior knowledge of perinatal loss and gather new knowledge surrounding the loss experience (Younas, 2020). By relating to the suffering of women and families experiencing perinatal loss, I can gather new knowledge through this literature review and ultimately develop a patient-centered resource manual to assist with the impact of suffering by providing enhanced support.

Prevalence of Perinatal Loss

Thirteen articles reviewed included information about the prevalence of perinatal loss. Perinatal loss is a health concern worldwide, with high loss rates noted despite economic and cultural factors, with one in four pregnancies ending in loss (Meyer et al., 2016; Power et al., 2022; Thornton et al., 2019; Trudeau et al., 2022; Tseng et al., 2014). In these articles, approximately 2.6 million stillbirths are reported globally each year (Meyer et al., 2016; Power et al., 2022; Thornton et al., 2019; Trudeau et al., 2022; Tseng et al., 2014). Limbo and Kobler (2010) report that more than 18,700 infants die in the first month of life, and 5,600 die from congenital disabilities in the first year. In the United States, over one million fetal deaths occur each year (Limbo & Kobler, 2010), with nearly 26,000 reportable stillbirths occurring after 20 weeks' gestation or more, with the rest resulting in miscarriages before 20 weeks' gestation (Limbo & Kobler, 2010). Reports of 14–20% of all pregnancies end in miscarriage (Trudeau et al., 2022), with Canada reporting 15% to 25% of pregnancies ending in miscarriage (PHAC, 2022). In Canada, between 2005 and 2014, the overall rate of perinatal loss varied between 7.5 and 8.1 per 1,000 total births, with the prevalence of congenital anomalies between 377.5 and 430.5 per 10,000 live births (Public Health Agency of Canada (PHAC), 2022).

Bereavement and Perinatal Loss

The PHAC (2022) describes genetic defects as the most common cause of perinatal loss. Specifically, for this literature review, my focus is unexpected terminations of pregnancy and the impact of the bereavement process surrounding the loss. For example, a genetic defect, such as Trisomy 18, is a difficult choice for parents. Trisomy 18 lacks prognosis, with some infants facing life-limiting conditions surviving only hours, days, weeks, or months postpartum (Abdel Razeq & Al-Gamal, 2021; Limbo & Kobler, 2010). When a fetus is found to have a congenital

anomaly, parents often go through stages of grief, like those who have experienced the loss of the infant. Parents voice mourning the loss of the “normal” healthy baby they envisioned and dreamed of for the future (PHAC, 2022; Power et al., 2022).

When a fetus is found to have a congenital anomaly, congenital disability, congenital disorder, or a congenital malformation, it is overwhelming to families when facing the decision of termination of pregnancy (Hendson & Davies, 2018; Lu, 2022; PHAC, 2022; Power et al., 2022). Congenital anomalies are usually structural or functional, mostly discovered during intrauterine life and can be identified prenatally, at birth or later in infancy (Hendson & Davies, 2018; PHAC, 2022). For this reason, the literature surrounding loss within the first 28 days of life is included in this review. Between 2005 and 2014, the prevalence of congenital anomalies in Canada varied between 377.5 and 430.5 per 10,000 live births (PHAC, 2022).

The Impacts of Perinatal Loss

Grief and Sorrow

Perinatal loss is often considered a "silent loss" (Ayebare et al., 2021; Kelley & Trinidad, 2012; Limbo & Kobler, 2010; Salgado et al., 2020; Tseng et al., 2014; Vivekananda et al., 2023). I found six qualitative studies of moderate design where society often does not acknowledge a perinatal loss and may try to diminish it, attempting to make the loss unremarkable along with the experience that women and families are enduring (Ayebare et al., 2021; Gundry et al., 2023; Kelley & Trinidad, 2012; Meyer et al., 2016; Salgado et al., 2020; Tseng et al., 2014). The Canadian Paediatric Society (CPS) has a position statement recommending that healthcare providers provide compassionate communication, bereavement support, sibling care, and counselling to families during perinatal loss. The CPS includes how perinatal loss often involves

biological failure, loss of identity, and declining hopes for the future which is also discussed in three studies of moderate quality (Hendson & Davies, 2018; Kalanlar, 2018; Rent et al., 2023). Further, five qualitative studies and one quantitative study examined how during an early miscarriage, there is no physical fetus to grieve, leaving the mind of women and families to mourn the possible relationship as opposed to tangible memories (Ayebare et al., 2021; Hendson & Davies 2018; Limbo & Kobler, 2010; Tseng et al., 2014). Complicating this notion of "silent loss" is the lack of formal documentation, such as live births and death certificates before 24 weeks gestation, inhibiting loss validation (Smith et al., 2020a). Parents have voiced that the lack of a publicly mourned loss or the socially accepted bereavement process leads to intense feelings of grief, sorrow, emptiness, and helplessness from the lack of validation identified, which was identified in three qualitative scholarly articles of medium quality (Fairchild & Arrington (2022); Salgado et al., 2020; Tseng et al., 2014). Ultimately, perinatal loss is often described as the most challenging loss a person can experience (Gundry et al., 2023; Henderson & Davies, 2018; Power et al., 2022; Robinson and Robinson, Esq., 2022).

Lack of Memories

Perinatal loss is described in four qualitative articles of moderate design and one quantitative article of moderate design as more remarkable than the loss of a spouse or a parent as hopes and dreams of the future are also mourned (Hendson & Davies, 2018; Kalanlar, 2018; Rent et al., 2023; Tseng et al., 2014; Vivekananda et al., 2023). Adjusting to perinatal loss is difficult because the death is often sudden and unexpected, with no memories or experiences to share (Hendson & Davies, 2018; Tseng et al., 2014). Because perinatal loss is often described as a silent loss, making memories during the immediate post-delivery period is essential due to the quick deterioration of the condition of the fetus after delivery at early gestations as discussed by

two scholarly articles (Power et al., 2022; Smith et al., 2020a). The fetus may sometimes show signs of life for an hour or more after birth, but parents are often not educated about that (Smith et al., 2020a). Subsequently, this is an important aspect to include in a PRM to educate and prepare parents for the appearance of, and possible rapid physical deterioration of the compromised fetus. Researchers have determined that the collection of fingerprints, handprints, and holding of the fetus post-delivery assists with creating essential memories for the long-term grieving process and should be offered with preparation to all families (Blood & Cacciatore (2014); Kalanlar, (2018); Smith et al., 2020a).

Mental Health Impacts

I found seven qualitative studies of moderate design where the association of perinatal loss and health disorders such as depression, anxiety, panic disorder, and PTSD were explored (Cambonie et al., 2023; Evans et al., 2022; Fairchild & Arrington, 2022; Garcia et al., 2020; Gundry et al., 2023; Roberts et al., 2021; Smith et al., 2020a; Smith et al., 2020b). Those experiencing perinatal loss are three times more likely to experience one of the mental health disorders listed above (Kalanlar, 2018). Six more qualitative studies of moderate design explored how women with a history of stillbirth express guilt that may last for months and years, and impacts their future subsequent pregnancies (Agwu Kalu et al., 2018; Evans et al., 2022; Kalanlar, 2018; Rent et al., 2023; Salgado et al., 2020; Smith et al., 2020b). The CPS acknowledges that other pregnancies are often complex following a perinatal loss, with women experiencing heightened anxieties, fear of reoccurrence, or symptoms of PTSD (Hendson & Davies, 2018).

In three scholarly qualitative articles of moderate design, I found that, unlike other bereavement experiences, the experience of stillbirth affects both parents concurrently, resulting

in restricted emotional support (Ayebare et al., 2021; Garcia et al., 2020; Power et al., 2022). In four articles, the loss of a child is described as a life-changing experience (Abdel et al., 2021; Kalanlar, 2018; Kelley & Trinidad, 2012; Stevenson et al., 2017) and emotional confusion is prevalent; with desire, sadness, loneliness, guilt, frustration, anger, and extreme emotional lability and sensitivity (Abdel et al., 2021; Ayebare et al., 2021; Cambonie et al., 2023; Hendson & Davies, 2018). The impact of perinatal loss on the mental health of parents is alarming. Healthcare providers must consider the range of psychological responses to perinatal loss and provide parents with education, support, and treatment options.

Support from healthcare providers during a perinatal loss is essential because of the improved care outcomes (Abdel et al., 2021). In the following sections, I will discuss the importance of bereavement training for healthcare providers, and the provision of bereavement training in nursing education.

Bereavement Training

Need for Structured Programs

Professional interventions provided by healthcare team members are crucial during perinatal loss. I found twelve articles about bereavement training. Eleven were qualitative studies of moderate quality (Abdel et al., 2021; Alghamdi & Jarrett, 2016; Ayebare et al., 2021; Garcia et al., 2023; Kalanlar, 2018; Kelley & Trinidad, 2012; Meyer et al., 2016; Power et al., 2022; Rent et al., 2023; Salgado et al., 2020; Tseng et al., 2014), with one cross-sectional study of moderate quality (Gundry et al., 2023). These studies reinforce the positive impact on grief, depression, and anxiety when written information from a support program is provided. This distressing time requires support for mothers and family members to handle the emotional

turmoil of perinatal loss (Power et al., 2022). In two qualitative studies of moderate design the impacts of a structured bereavement program in the Neonatal Intensive Care Unit (NICU) that is readily available for parents and healthcare providers was explored. The structured program was associated with positive impacts of improved coping when the bereavement program is provided prior to the losses (Abdel et al., 2021; Rent et al., 2023). These authors found that when a structured program is offered to assist with bereavement in the NICU, the enhanced support given to prepare women and families for the loss lessens the effect of mental health consequences both during and after the loss experience. Abdel Razeq and Al-Gamal (2021) and Alghamdi and Jarrett (2016) conducted phenomenological qualitative studies of moderate design to understand the needs of grieving mothers who experience the death of neonate infants in the NICU surrounding the time they were informed about the death of their infants. These authors discovered the importance of nurses understanding mothers' responses to loss and having more training in bereavement care. Being informed, being supported, and being with the patient are three core categories of bereavement care essential for grieving families (Abdel et al., 2021). Enhanced support post-loss leads to improved care outcomes by lessening the effects of PTSD, depression, and anxiety (Abdel et al., 2021).

Impacts of a Structured Program

I found three articles where the specific impacts of structured programs for bereavement post pregnancy loss were explored (Alghamdi and Jarrett, 2016; Hung et al., 2023; Power et al., 2022; Rent et al., 2023; Smith et al., 2020a). The supportive role of maternity and neonatal nurses and other healthcare providers in dealing with complicated emotions was absent from participant mothers' experiences in the qualitative study of moderate design by Power et al. (2022). Power et al., (2022) conducted a descriptive study to explore the experiences and

perceptions of perinatal bereavement care. The participants felt a lack of support from healthcare providers when dealing with their complicated emotions during their perinatal loss despite Alghamdi and Jarrett (2016) suggesting the interactions of bereaved parents with health professionals profoundly affects their capacity to cope with their loss. Alghamdi and Jarrett (2016) completed a qualitative study of moderate design. They discovered that if bereavement care is managed poorly, there are consequences for altered mental health in the immediate phase after a perinatal loss as well as after discharge from the hospital following a perinatal loss. Rent et al. (2023) conducted a qualitative descriptive study of moderate design sharing the perspectives of healthcare providers regarding neonatal bereavement. Using semi-structured interviews, Rent et al. (2023), discovered that midwives are often concerned about the degree of grief expressed, with many parents not wanting to acknowledge the loss. Of note, none of Rent et al. (2023) study sites included dedicated palliative care providers or staff assigned to supporting mothers and families after neonatal death despite evidence in the literature surrounding the importance of perinatal loss and bereavement care support (Ayebare et al., 2021; Gundry et al., 2023; Kelley & Trinidad, 2012; Meyer et al., 2016; Salgado et al., 2020; Tseng et al., 2014).

Caring for parents inappropriately during a perinatal loss can lead to devastating and long-lasting consequences that can severely affect a woman and her partner's grieving journey (Power et al., 2022). Perinatal bereavement care must encompass the physical, psychological, emotional, and spiritual support from a multidisciplinary team providing care to the bereaved parents, their families, siblings, and grandparents (Kalanlar, 2018; Power et al., 2022).

In the next section, I will discuss information to be included in a structured structured program.

Content to be Included in a Structured Program

I found six articles about information to be included in a bereavement support program (Ayebare et al., 2021; Garcia et al., 2020; Gundry et al. 2023; Kalanlar, 2018; Power et al., 2022; Rent et al., 2023). Garcia et al. (2020) and Power et al. (2022) completed qualitative studies of moderate design that explored how the COVID-19 pandemic created extraordinary and additional demands for midwives providing bereavement support. It significantly disrupted human connection and communication (Power et al., 2022), leading to gaps in support and informed care surrounding the termination and bereavement process. This is important because as we move forward beyond the pandemic, standard human connection and communication remain disrupted. A web based PRM can be developed to support the disrupted communication and support by acknowledging the identified gaps in support and informed care during the pandemic found (Garcia et al., 2020; Power et al., 2022). Kalanlar (2018) conducted a qualitative descriptive study to provide comprehensive and current information on hospital practices following perinatal death. Kalanlar (2018) recommends that hospitals develop policies related to loss and grieving to ensure that families are treated respectfully and provided with appropriate and adequate information, that consider parents' choices. Rent et al. (2023) discovered the importance of incorporating patient preference into bereavement care when completing end-of-life care in the NICU. Gathering patient preference prior to the experience of the loss may assist with lessening mental health impacts of women and families and lessen incidences of PTSD by providing grief support preferred by women and families.

Smith et al. (2020a) used grounded theory to explore the healthcare experiences of parents whose babies died between 20 and 24 weeks of gestation, with the aim to identify practical ways to improve healthcare delivery. Smith et al. (2020a) indicate that the language

used by healthcare providers can lead to miscommunication surrounding expectations, such as the number of terms surrounding perinatal loss. These authors determined that most participants felt the term miscarriage does not associate with giving birth. The pain and physicality of labour lead to confusion during the termination of pregnancy when using the term miscarriage. Smith et al. (2020b) completed a qualitative study of moderate design which highlights an example of miscommunication. For example, parents describe how being told then are having a miscarriage at 21 weeks following a fetal anomaly diagnosis does not prepare them for the experience of labour induction, significantly adding to the distress.

Ayebare et al. (2021) conducted a qualitative descriptive study to explore the influence of cultural beliefs and practices on the experiences of bereaved parents and healthcare workers after stillbirth. Ayebare et al. (2021) acknowledge culture as a complex and powerful influence on parents' experiences after the death of their baby; affecting parents' reactions, decision-making, coping mechanisms, and the support available from others when a baby is stillborn.

Hung et al. (2023) completed a randomized controlled trial (RCT) of strong design with a prospective pre-test-post-test experimental design to investigate the effect of a mental health website intervention on perceived stress, depression, sleep quality, and social support in women with recurrent miscarriage. Hung et al. (2023) found improved depressive symptoms and improved sleep quality of women who received information on the mental health website for perinatal loss. Web-based interventions offering mental health support are a flexible solution to address barriers to care, such as social distancing during the pandemic (Hung et al., 2023). These authors also highlight an advantage of e-healthcare interventions is the freedom from time and place restrictions, allowing access to the information after discharge. A website is a cost-

effective intervention to improve quality of life and psychological well-being to facilitate self-empowerment in women suffering from perinatal loss (Hung et al., 2023).

Gundry et al. (2023) conducted a qualitative study of moderate design, and similar to Hung et al. (2023), suggested that bereavement support programs should incorporate a variety of sections that enable bereaved parents to connect to varying support routes, including sending personalized cards, information about grief support groups, memorial events, counselling and therapy, and legacy work through a newsletter. Gundry et al. (2023) completed a cross-sectional study of moderate design that evaluates a Bereavement Support Program (BSP) from the perspectives of both families and service providers. These authors concluded that a support program newsletter is highly effective as additional support and assists with the interaction of the bereavement program. They noted improved self-reported grief rates of 78% of participants who voiced appreciating written information from the support program (Gundry et al., 2023). As well, 85% of participants highly appreciated the newsletter that offered support and interaction with bereavement program.

In the next section, I will discuss nursing education regarding the bereavement process in perinatal loss. This is important because the literature suggests nurses struggle with communication with parents experiencing termination of pregnancy, necessitating the need for more education and hands-on practice.

Nursing Education on Bereavement Training

Current nursing education fails to provide essential, practical information regarding perinatal loss and the management of bereavement for women and families (Alghamdi & Jarrett, 2016). I found four qualitative studies of moderate quality, one cross-sectional of moderate design, and one mixed-method study of moderate design where nursing education and

bereavement care were explored (Alghamdi & Jarrett, 2016; Agwu Kalu et al., 2018; Gundry et al., 2023; Power et al., 2022; Rent et al., 2023; Smith et al., 2020a). Unfortunately, there is a scarcity of literature regarding communication strategies for end-of-life and bereavement care for neonates, their mothers, and their families (Rent et al., 2023).

Agwu Kalu et al. (2018) conducted a mixed methods sequential explanatory study of moderate design to explore psychosocial factors that impact midwives' confidence in providing bereavement support to parents who have experienced a perinatal loss. In this study, a convenience sample size of 277 midwives' students felt that midwifery schooling does not provide any hand-on training surrounding bereavement care and students did not feel adequately prepared for bereavement care upon graduation. These authors note that participants felt the current delivery of perinatal bereavement care education for midwives needs to meet their clinical practice needs and include more hands-on bereavement care. Similarly, Gundry et al. (2023) acknowledge a considerable gap between empirical recommendations and clinical practice, with numerous barriers to improving bereavement care, such as a lack of hands-on experience in the clinical area during training. Many students voice feeling turned away from bereavement patients (Gundry et al., 2023). In this study, participants felt a gap in their knowledge of providing appropriate perinatal bereavement support to different grieving parents, including a lack of communication skills. Agwu Kalu et al. (2018), Power et al. (2022), and Smith et al. (2020a) provide support for the lack of hands-on practice in nursing education that may limit the delivery of bereavement nursing care.

It is important for nurses to have access to hands-on experience with bereavement care. The specialized training of bereavement care is not something that is fully learned in a textbook and requires hands-on clinical familiarity because each perinatal loss scenario is unique (Agwu

Kalu et al., 2018). Moving forward, recognizing the lack of training during nursing education for bereavement care, the PRM can enhance bereavement support provided by novice RNs.

Conclusion

In this literature review, I have explored perinatal loss and have reviewed 15 qualitative, two quantitative, and three mixed-method studies. Overall, I have determined that a knowledge gap exists for women and families undergoing a termination of pregnancy. Patients and families lack education prior to the procedure which results in increased unnecessary suffering, as well as increased incidences of mental health concerns. While I found consistent ideas surrounding unexpected terminations of pregnancies, such as a lack of communication and education provided to parents, there is a limited amount of research available on the effectiveness of interventions in the bereavement process. Perinatal loss is a prevalent health concern, with vast mental health impacts for the sufferers. Strategies to address the knowledge gap surrounding the termination of pregnancy and the bereavement process are warranted.

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Appendix B: Literature Summary Tables

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Agwu Kalu et al., (2018)</p> <p><u>Design:</u> A mixed methods sequential explanatory design.</p> <p><u>Purpose:</u> To explore the psychosocial factors that impact midwives' confidence to provide bereavement support to parents who have experienced a perinatal loss.</p>	<p><u>N:</u> A convenience sample size of 277 midwives was used to achieve a 95% confidence level.</p> <p><u>Country/setting:</u> Three large public maternity teaching hospitals in urban Ireland.</p> <p>Group 1: 277 midwifery participants.</p> <p>Group 2: A purposive sample of 11 willing respondents split into two focus groups for interviews.</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ Data saturation occurred after the second focus group. ○ Rigour ensured credibility, transferability, dependability, and confirmability. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Multivariate analyses were used to analyze the quantitative data (t-test, ANOVA, Tukey's post-hoc test) tools tested to ensure reliability and validity. 	<p>Themes:</p> <p>(1) Bereavement support skills Only 18.7% (SD = 5.84) of staff felt they had adequate support scores. Midwives with less than 1 year of practice had less bereavement skills for providing support to parents who had experienced a perinatal loss (p = 0.015).</p> <p>(2) Bereavement support skills All participants disclosed gaps in their knowledge on how to provide appropriate perinatal bereavement support to different grieving parents, including communication skills. Participants acknowledged that although there was some support from their organization, more supported was needed for debriefing opportunities and counselling services.</p>	<p><u>Strength of Design:</u> Strong</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • Convenience sampling • Unclear if assessors were trained in data collection. • Participants recruited only from one healthcare authority with convenience sampling affecting generalizability. • Newly designed questionnaire utilized, therefore tests not known to support reliability

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Alghamdi & Jarrett (2016)</p> <p><u>Design:</u> A phenomenological qualitative study.</p> <p><u>Purpose:</u> To explore the experiences of final-year student midwives when caring for women with perinatal loss.</p>	<p><u>N:</u> Two focus groups were conducted, comprising ten final-year student midwives who were completing a BSc (Hons) Midwifery program.</p> <p><u>Country/setting:</u> a United Kingdom (UK) higher education institution.</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ Convenience sampling ○ Strategies such as writing memos and keeping a reflective diary keeping ensuring credibility and trustworthiness of the study. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Thematic analysis, with the initial phase of the analysis involving complete reading of transcripts followed with identification of codes, as they relate to the aims and objectives of the research. 	<p>Themes:</p> <p>(1) Preparation for perinatal loss</p> <ul style="list-style-type: none"> • Unprepared in caring for grieving parents. • More hands on experienced needed. <p>(2) ‘Just dealing with it’</p> <ul style="list-style-type: none"> • Several students believed that being able to cope with traumatic situations, including bereavement, was character building <p>(3) Contradiction and challenges with the role of the midwife</p> <ul style="list-style-type: none"> • Students preferred to keep busy and felt awkward being with a bereaved woman unless they were engaged in some activity. <p>(4) Emotional impact and coping strategies</p> <ul style="list-style-type: none"> • Self-reflection used by most students when coping with bereavement and loss. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • Clinical instructor completed focus group discussions/notes and analysis, leaving room for bias but some steps (second researcher, note review) to assist with researcher influence. • No locating the researcher culturally or theoretically.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Ayebare et al. (2021)</p> <p><u>Design:</u> A qualitative descriptive study design.</p> <p><u>Purpose:</u> To explore the influence of cultural beliefs and practices on the experiences of bereaved parents and healthcare workers after stillbirth.</p>	<p><u>N:</u> Parents (N = 134) who experienced a stillbirth (≤ 1 year) and health workers (N = 61) providing bereavement care.</p> <p><u>Country/setting:</u> Five facilities in Uganda and Kenya.</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ Face-to-face interviews with all the participants, at least six weeks after stillbirth by trained research assistances, separate from the researcher's supporting rigour. ○ location of interviews selected by participant. ○ Field notes utilized to note nonverbal cues. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ No new codes were identified at the conclusion of analysis was used to establish an end, rather than data saturation. ○ Recapping at the end of each interview was used rather than returning scripts to participants ○ Interview data were analyzed thematically, using a four-stage approach which included re-reading, notes on patterns, formal manual coding into themes. 	<p>Themes:</p> <p>(1) 'Gathering round'</p> <ul style="list-style-type: none"> • Support system essential to coping and beginning moving forward after stillbirth <p>(2) 'It is against our custom'</p> <ul style="list-style-type: none"> • Regret expressed for not seeing or holding the baby • Missed opportunities to create memories. <p>(3) 'Maybe it's God's plan or witchcraft'</p> <ul style="list-style-type: none"> • Not all participants took comfort from predetermined by a higher power, several described their faith being tested. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • Not clear whether data saturation was reached.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Blood and Cacciatore (2014)</p> <p><u>Design:</u> A qualitative study.</p> <p><u>Purpose:</u> To understand parents' experiences and opinions toward the understanding of best practice in perinatal bereavement photography.</p>	<p><u>N:</u> 104 parents</p> <p><u>Country/Setting:</u> Arizona, United States</p> <p><u>Participants:</u> 104 participants suffering perinatal loss, recruited from a broader research project whose children died at any age.</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ Data from parents whose children died perinatally (N=132) were recruited ○ an anonymous internet survey with open- and closed-ended questions was given to parents ○ Participants who provided no answers to questionnaire were excluded. ○ Eight responses were removed due to ubiquitous in broader data. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Data were inductively analyzed for responses that could specifically inform photography practice. ○ Useful responses placed into two categories then grouped into themes. 	<p>Themes:</p> <p>(1) Obstacles to postmortem photography</p> <ul style="list-style-type: none"> • Physical and emotional shock voiced. • 35 participants report rapidly unfolding events lead to delayed processing. • 26 participants did not consider the memorial photography during crisis. <p>(2) Obtaining Consent for photography</p> <ul style="list-style-type: none"> • 35 participants endorsed healthcare providers strongly recommending photos. • Being asked more than once was helpful. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • Incongruence between interpretive interview and survey • No statement on philosophical orientation or methodology • Disregarded single reported meanings • No statement of cultural and theoretical orientation.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Cambonie et al. (2023)</p> <p><u>Design:</u> A prospective observational study</p> <p><u>Purpose:</u> To determine whether the context of death—after a decision of withholding or withdrawing life-sustaining treatment (WWLST) or despite maximum care—was associated with subsequent risk of parental anxiety or depression.</p>	<p><u>N:</u> all infants who died in a five-year period in NICU. 190 infants died during the study period. 179 were eligible for study.</p> <p><u>Country/setting:</u> The University Hospital of Montpellier (France)</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ Face-to-face semi-structured interviews with parents three months after the infant’s death ○ Anxiety and depression were measured using Hospital Anxiety and Depression Scale (HADS) questionnaires, completed by parents 5 and 15 months after death <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Comparisons were made using the Fisher, chi-squared, Student, and Wilcoxon-Mann-Whitney tests of HADS. ○ Of the 179 bereaved parents, 109 (61%) attended the 3-month interview demonstrating some loss to follow-up. 	<p>Themes:</p> <p>(1) Relationship to parental gender</p> <ul style="list-style-type: none"> • Anxiety rates were higher in mothers than in fathers at five months ($p=0.034$) and 15 months ($p=0.034$). • Depression rates were comparable between mothers and fathers at five months ($p=0.87$) and 15 months (0.26). <p>(2) Relationship to the circumstance of death</p> <ul style="list-style-type: none"> • No association found between circumstance of death and parental anxiety. <p>(3) Relationship to parental agreement with the decision of WWLST</p> <ul style="list-style-type: none"> • Parental agreement after the multidisciplinary ethics meeting was associated with higher risks of anxiety at 5 months ($p=0.005$). 	<p><u>Strength of Design:</u> Strong</p> <p><u>Quality:</u> Moderate</p> <p>Issues:</p> <ul style="list-style-type: none"> • The principle investigator completed interviews, leaving room for influence on the participants • No statement locating researcher/interviewer culturally or theoretically • No mention of ethical approval by an appropriate body. Informed consent discussed and collected. No mention of confidentiality attempts.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Evans et al. (2022)</p> <p><u>Design:</u> A qualitative descriptive design</p> <p><u>Purpose:</u> To gain a deeper understanding of African American women's stressors prior to, during, and after suffering each type of fetal/infant loss: miscarriage, stillbirth, and infant mortality.</p>	<p><u>N:</u> Seven African American women who specifically experienced all three types of fetal/infant loss</p> <p><u>Country/setting:</u> Northeast Ohio, United States</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ Theoretical premise identified with two research questions to guide the study. ○ Semi-structured interviews because they allowed researchers the opportunity to ask participants open-ended questions and follow-up responses. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Audio files were transcribed verbatim using QSR International's NVivo 12 transcription software ○ Quantitative questionnaires of demographic data were inputted into IBM's SPSS. ○ All authors read transcripts several times before coding. ○ Descriptive coding followed by thematic analysis was completed. ○ sufficient data to support findings and conclusions, and used peer consultation to enhance credibility. 	<p>Themes</p> <p>(1) Social Support</p> <ul style="list-style-type: none"> • A common stressor, ineffective communication with family and friends about the loss of their infant difficult. • Social support is the largest stressor <p>(2) Pregnancy, Delivery, and Death of Child</p> <ul style="list-style-type: none"> ○ Stress that came with the uncertainty and unknown surrounding loss and delivery. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • \$100 gift card given to participants, potential for incentive-caused bias • Two of the female researchers conducted the interviews with similar characteristics as participants to increase trust, leaving a potential for influence during data collection. The researchers do not address relationship. • One participant audio recording was discarded because the secession was not completed entirely.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Fairchild & Arrington (2022)</p> <p><u>Design:</u> A qualitative descriptive study design</p> <p><u>Purpose:</u> To better understand the connections between loss, identity, and lived experience of miscarriage.</p>	<p><u>N:</u> 24 women who had experienced a miscarriage</p> <p><u>Country/setting:</u> United States</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ Three research questions discussed. ○ A semi-structured, flexible approach that allowed participants to highlight their important issues. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ After recording and transcribing both authors compared notes across interviews to find noteworthy themes within interview they noted as the constant comparison method ○ Chronological order assessment of the transcripts, multiple reviews using used a broad open coding system to emerge commonalities. 	<p>Themes:</p> <p>(1) Post-Miscarriage uncertainty and anxiety</p> <ul style="list-style-type: none"> • Uncertainty due the lack of medical information they received. • Distressed and frightened because they did not know what to expect during the miscarriage. <p>(2) Grief after miscarriage</p> <ul style="list-style-type: none"> • Most participants used term “baby”, rather than referring the unborn child as a fetus, or tissue, or a lump of cells. 	<p><u>Strength of Design:</u> Weak</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • Research questions are narrow, they do not have congruity with the study’s approach of a flexible semi-structured interview. • Researchers are not located culturally or theoretically • Influence of researchers on research not addressed researchers completed the interviews.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Garcia et al. (2020)</p> <p><u>Design:</u> A qualitative descriptive study design</p> <p><u>Purpose:</u> To explore the experiences of bereavement after stillbirth of Pakistani, Bangladeshi, and White British mothers</p>	<p><u>N:</u> A purposive sample of six Pakistani, Bangladeshi, and White British mothers over the age of 16 identified by a gatekeeper</p> <p><u>Country/setting:</u> A town with multi-ethnic populations in England.</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ A semi-structured topic guide was developed for face-to-face interviews ○ Interviews were recorded and passed back to participant for validation of the transcript establishing confirmability ○ ethical and methodological considerations guided by the framework for ethical decision making. ○ Interviews conducted by a RN, not the researchers. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Auto-recordings were transcribed by the interviewer RN and checked by author for trustworthiness. ○ Demographic data entered in Microsoft Excel. ○ Framework analysis used versus thematic. 	<p>Themes:</p> <p>(1) Knowledge and information of pregnancy and perinatal mortality</p> <ul style="list-style-type: none"> • Desire for more information • Limited knowledge on risk factors and felt unprepared for adverse delivery outcomes. <p>(2) Experiences with maternity care</p> <ul style="list-style-type: none"> • Poor communication was evident with a few mothers' bereavement experiences, resulting in unnecessary distress for the mother. • did not warn the mother of the visually deteriorated (i.e., macerated) state of the baby • no staff checked what specific and appropriate support was available to the mother <p>(3) Attitudes and perceptions to pregnancy and perinatal mortality</p> <ul style="list-style-type: none"> • Anxiety experienced around the unfolding of something wrong with their baby. • Anxiety learning their baby will die • Anxiety for future pregnancies. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • Only one participant was provided transcript for validation, limiting trustworthiness. • No research questions or objectives identified. • Researchers do not locate themselves culturally or theoretically.

Study/Design	Methods	Key Results	Comments
<p><u>Author:</u> Gundry et al. (2023)</p> <p><u>Design:</u> A cross-sectional study design.</p> <p><u>Purpose:</u> To evaluate a Bereavement Support Program from the perspectives of both families and service providers.</p>	<p><u>N:</u> 102 bereaved parents and staff members of bereavement support program</p> <p><u>Country/setting:</u> Queensland, Australia.</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ Random sampling technique was used after purposive sampling for hospital selection. ○ Written questionnaire form with 130 questions based on Canadian hospitals maternity policies and practices. ○ Data were entered directly by respondents into the online software platform. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Data descriptively summarized with proportions, means and standard deviations. ○ Thematic content analysis was used, with theme discussion with refined by the research team. 	<p>Themes:</p> <p>(1) Introduction to the Bereavement Support Program</p> <ul style="list-style-type: none"> • 78% of participants discuss positive impact on grief with written information from the support program. • Timing of introduction crucial, not useful immediately during process of death of child. <p>(2) Receiving the “Living Forward” Newsletter</p> <ul style="list-style-type: none"> • Highly appreciated (85%) the newsletter that offered support and interaction with bereavement program. <p>(3) Contacting the Bereavement Support Program for Support</p> <ul style="list-style-type: none"> • Contact to the program initiated by parents was only 25%. • Counselling from the program was most frequently utilized by contacting the support program. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • Data collection methods and generation of themes not congruent as a survey questionnaire was utilized versus face-to-face with open-ended questions • Close-ended survey questions analyzed with thematic analysis. • Low response rate of 16% of convenience sample.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Hung et al. (2022)</p> <p><u>Design:</u> A randomized controlled trial with a prospective pre- test- posttest experimental design</p> <p><u>Purpose:</u> To investigate the effect of a mental health website intervention on perceived stress, depression, sleep quality, and social support in women with recurrent miscarriage</p>	<p><u>N:</u> 62 participants total</p> <p><u>Country/setting:</u> Obstetrics and gynecology clinics of a medical center hospital in southern Taiwan.</p> <p><u>Experimental group:</u> N=31. Received access to the mental health website intervention during the 12-week genetic testing period.</p> <p><u>Control group:</u> N=31. Received standard medical care only.</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ Tools known to be reliable and valid, such as Edinburgh Depression Scale (sensitivity of 92% and test-retest reliability score of .81) and statistical testing adequate with reports of paired sample t-tests. ○ The means for pretest and posttest measures show no significant difference between pre and posttest. ○ Random sampling with similar baseline characteristics <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ IBM SPSS Statistics used for data analysis. ○ Internal consistency reported (Cronbach's $\alpha=0.75$). 	<p><u>Themes:</u></p> <p>(1) Reducing perceived stress and depression in women</p> <ul style="list-style-type: none"> • Statistically significant pretest/posttest reductions in mean scores of depressions and stress scale posttest scores in the experimental group indicates the effectiveness of the developed website intervention in helping users self-manage their depression and perceived stress ($p = .023$) <p>(2) Improved sleep quality</p> <ul style="list-style-type: none"> • by providing resources for the management of depressive symptoms and perceived stress, a secondary benefit of improved sleep was discovered. • E-healthcare interventions allows for freedom from time and place restrictions, allowing access of information after discharge 	<p><u>Strength of Design:</u> Strong</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • Generalizability weak as recruitment from one singular clinic. • Fairly high loss to follow-up, 16.2% attrition rate. • Single blinded with no discussion of training in data collection. • Small sample size.

Study/Design	Methods	Key Results	Comments
<p>Author: Kalanlar (2018)</p> <p>Design: A qualitative descriptive study</p> <p>Purpose: To provide comprehensive and current information on hospital practices following perinatal death</p>	<p><u>N</u>: A purposive sampling method was used to recruit 49 hospitals.</p> <p><u>Country/setting</u>: Three provinces in Turkey: Ankara, İstanbul, and İzmir.</p> <p><u>Data collection and outcomes</u>:</p> <ul style="list-style-type: none"> ○ Random sampling technique was used after purposive sampling for hospital selection ○ Written questionnaire form with 130 questions based on Canadian hospitals maternity policies and practices <p><u>Analysis</u>:</p> <ul style="list-style-type: none"> ○ Data analysis was performed with statistical software ○ Data reviewed by field experts with a PhD in public health, pediatrics, and gynecology 	<p>Themes:</p> <p>(1) Remembrance pack</p> <ul style="list-style-type: none"> • The most problematic and available at most hospitals. <p>(2) Seeing and holding the deceased baby</p> <ul style="list-style-type: none"> • 93.1% of the hospital encourage parents to see the deceased baby to form memories for the stages of grief. <p>(3) Support by a spiritual advisor and social worker</p> <ul style="list-style-type: none"> • only one in five hospitals reported that they provided a spiritual advisor. • Only one in six hospitals (16.3%) reported that they provided a social worker 	<p><u>Strength of Design</u>: Moderate</p> <p><u>Quality</u>: Medium</p> <p><u>Issues</u>:</p> <ul style="list-style-type: none"> • No research questions or objectives identified. • Not clear whether data saturation was reached. • Random sampling not used; A purposive sampling method utilized • Data collection method is a form questionnaire, which is not congruent with descriptive theme generation. • Do not locate the researcher theoretically or culturally. • Cannot tell how participants are purposively recruited.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Kelley and Trinidad (2012)</p> <p><u>Design:</u> A secondary qualitative analysis of transcript data from three semi-structured focus groups conducted with parents who had experienced a stillbirth and delivered in a hospital, and 2 focus groups with obstetrician-gynecologists</p> <p><u>Purpose:</u> To offer an in-depth account of parents' experiences of stillbirth within the context of the clinical encounter, with particular attention to the emotional and personal accounts of parents, their perceptions of communication and support while in hospital and following, and their process of grief and attempts to give meaning to their child's death.</p>	<p><u>N:</u> No report of number of participants in each focus group.</p> <p><u>Country/setting:</u> The greater Seattle region in Washington State</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ Participants were identified and recruited through parent hospital guild groups and then by snowball recruitment through friends of guild members. ○ The first author developed the coding scheme based on a first read through the transcripts from physician and parent focus groups, a literature review, and a second line-by-line read to identify central themes and concepts. ○ Three semi-structured focus groups with open-ended questions. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Conduction of a thematic discourse analysis of transcripts was complete, with attention to how parents and physicians experienced the loss of a stillborn infant. ○ Sessions were audio-recorded and transcribed for analysis. 	<p>Themes:</p> <p>(1) Knowledge/ awareness</p> <ul style="list-style-type: none"> • Shocked and unprepared, did not expect stillbirth to happen. • Wanting to know the cause of death and not being able to get answers was frustrating. <p>(2) The stillborn child is real and will always be remembered as part of their family</p> <ul style="list-style-type: none"> • Importance of naming child • Importance of receiving legitimate documentation, such as a death certificate at the very least. <p>(3) Post-stillbirth care</p> <ul style="list-style-type: none"> • Desperate for more information on causes, prevention, and support resources • Parent support groups and online groups noted to be helpful. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • Do not locate the researcher theoretically or culturally. • Potential for bias with the interviews being conducted by first author. • Second author not invited to analysis until after first author completed a rough draft of analysis. • Study is from a secondary analysis of focus group data of an informal needs assessment to inform a new program focused on prematurity and stillbirth, limiting the authors' ability to change design.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Meyer et al. (2016)</p> <p><u>Design:</u> A mixed-methods prospective study of bereaved mothers</p> <p><u>Purpose:</u> To better understand the complex process of grieving and how social and cultural frameworks shape mothers' experience of infant loss.</p>	<p><u>N:</u> a convenience sample of 153 mothers who were 18 or older</p> <p><u>Country/setting:</u> Komfo Anokye Teaching Hospital (KATH) in Kumasi, Ghana and is largest teaching hospital in Ghana and houses a Mother Baby Unit (MBU) that cares for 4,500 sick and premature newborns annually.</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ A semi-structured interview and a quantitative survey about demographics, loss, and mental health and open-ended questions about the infant's death, reactions of family and hospital staff, social support, and cultural issues related to loss. ○ Interviews were performed by a joint team of second-year American medical students, not the researchers preventing researcher influence. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Interviews were recorded and transcribed verbatim. ○ coded transcripts to identify common themes using content analysis 	<p>Themes:</p> <p>(1) Isolation vs. seeking support within the community</p> <ul style="list-style-type: none"> • Most tears were cried during alone time and being around people helps sorrow. <p>(2) Trust in God</p> <ul style="list-style-type: none"> • Telling oneself its gods will helps with coping • Leave everything to God and worry less. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • No statement locating researchers theoretically or culturally.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Power et al. (2022)</p> <p><u>Design:</u> A qualitative descriptive design.</p> <p><u>Purpose:</u> To explore the experiences and perceptions of midwives providing perinatal bereavement care during the COVID-19 pandemic and to identify the barriers and facilitators to delivering compassionate bereavement care.</p>	<p><u>N:</u> A purposeful sample of eleven midwives.</p> <p><u>Country/setting:</u> A independent regional maternity hospital located in a large urban center in Ireland.</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ in-depth, semi structured audio recorded interviews (face-to-face or phone call). ○ Research question congruent with phenomenological approach. ○ Data saturation achieved meaning all data collected. ○ Rigour achieved by prolonged engagement with data improving creditability. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Thematic data analysis was carried out in six-step structured framework which is known to reduce bias ○ Use of descriptive codes and adding new codes as analysis progressed ○ Further analysis to ensure themes are relevant to the research question 	<p>Themes:</p> <p>(1) Challenges of providing compassionate bereavement care during a pandemic</p> <ul style="list-style-type: none"> • Personal Protective Equipment (PPE) affected care provision to bereaved parents and a significant barrier to providing compassionate care • Lack of support person <p>(2) Psychological effect and coping strategies utilized by midwives during a pandemic</p> <ul style="list-style-type: none"> • Therapeutic touch hindered during pandemic • unknown effects of COVID-19 infection for pregnant women and the possible link of infection to miscarriage and stillbirth. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p><u>Issues:</u></p> <ul style="list-style-type: none"> • Researcher discloses establishing a trusting relationship before interviewing participants, revealing the potential of the researcher to influence the study. • The researcher does not identify cultural or theoretical orientation.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Rent et al. (2023)</p> <p><u>Design:</u> A qualitative descriptive design grounded theory approach</p> <p><u>Purpose:</u> To contribute to the growing body of knowledge on neonatal bereavement by sharing the perspectives of health care providers in Ethiopia and Ghana</p>	<p><u>N:</u> A purposive sample of 40 nurses, midwives, medical trainees, and senior physicians.</p> <p><u>Country/setting:</u> Three hospitals in 2 major cities- Ethiopia and Ghana</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ Semi structured interviews were complete, themes summarized and transcribed verbatim. ○ a series of open-ended questions with follow-up prompts when appropriate. ○ Data saturation achieved. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Transcribed interviews were input into NVivo 10.0 ○ Theme generation and preliminary coding completed. ○ A comparative analysis was performed to assess if key differences in themes arose between interviewees from different countries or hospital sites. 	<p>Themes:</p> <p>(1) Concern for the Degree of Grief Expressed</p> <ul style="list-style-type: none"> • providers mentioned the importance of having a conversation with the mother before the death occurred, to try and prepare them for the loss. <p>(2) Impact of Losing a Newborn</p> <ul style="list-style-type: none"> • Lack of public grieving. • Avoidance of discussion of loss. <p>(3) Practical Barriers</p> <ul style="list-style-type: none"> • High volume of patients and insufficient staffing. • No staff assigned to supporting mothers and families after neonatal death. • Lack of space for counseling. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • No statement clarifying cultural or theoretical orientation. • Potential for bias with the interviews being conducted by a visiting physician. • Recruitment via a poster at three facilities, then purposive sampling methods not clear.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Smith et al. (2020) a</p> <p><u>Design:</u> A qualitative interview study using grounded theory.</p> <p><u>Purpose:</u> To explore the healthcare experiences of parents whose baby died between 20 and 24 weeks of gestation to identify practical ways to improve healthcare delivery.</p>	<p><u>N:</u> Interviews were undertaken with 38 parents: 10 parent pairs and 18 mothers</p> <p><u>Country/setting:</u> Four participating clinical sites in England</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ A purposive sample of parents. ○ An advisory panel involved validity of findings. ○ Semi-structured in-depth narrative interviews. ○ Interviews were transcribed verbatim with transcripts provided to participants for editing <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Emerging themes were identified using a ‘modified grounded theory’ approach with verification by the researchers and the advisory panel. ○ Advisory panel of parents, clinicians and advocacy grouped involved to ensure validity of findings. 	<p>Themes:</p> <p>(1) The importance of terminology</p> <ul style="list-style-type: none"> • Felt using the term miscarriage was inappropriate and did not adequately describe their lived experience of losing a baby. <p>(2) Being prepared for labour and birth</p> <ul style="list-style-type: none"> • Miscarriage term not associated with giving birth and the pain and physicality of labour. <p>(3) Memory making</p> <ul style="list-style-type: none"> • Memories during the immediate post-delivery phase is essential for the grief process. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • No discussion of data saturation achievement. • Discard of single reported meaning with one interview lost to follow-up. • Researchers do not locate themselves theoretically or culturally.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Smith et al. (2020) b</p> <p><u>Design:</u> A qualitative cross-sectional study</p> <p><u>Purpose:</u> To examine maternity and neonatal healthcare professionals' perceptions and experiences of offering to bereave parents and using a cold cot following the loss of a baby.</p>	<p><u>N:</u> 33 maternity and neonatal unit healthcare professionals who worked across three UK hospital settings</p> <p><u>Country/setting:</u> Two Neonatal Intensive Care Units (NICU) and three Central Delivery Suites (CDS), comprising a range of service size and located across three hospitals in the Southwest of England</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ Recorded, semi-structured interviews ○ Twenty-seven face-to-face and 6 telephone interviews ○ Recorded interviews were transcribed verbatim by university students, and researchers checked a random sub-sample of transcripts to ensure quality <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Data were analyzed using inductive reflexive thematic analysis. ○ Transcripts were subjected to thematic analysis. 	<p>Themes:</p> <p>(1) Perceived benefits of using a cold cot</p> <ul style="list-style-type: none"> • Positive views technology • Able to keep the rapid deterioration is the primary advantage identified <p>(2) Scenarios of technology use</p> <ul style="list-style-type: none"> • The cooling cot was great for parents who wanted to spend time with baby • Other half of parents felt they did not want it, and wanted to be discharged out of hospital quickly. <p>(3) Introduction of the technology to parents</p> <ul style="list-style-type: none"> • Noted timing often difficult to bring up discussion regarding technology. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • A single reported transcription was discarded as the interview was interrupted, leaving analysis of data compromised • The researchers do not locate themselves culturally or theoretically.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Tseng et al. (2014).</p> <p><u>Design:</u> A qualitative Descriptive design to describe and explore women's experiences and responses to stillbirth.</p> <p><u>Purpose:</u> To describe the process of Taiwanese women's recovery from stillbirth.</p>	<p><u>N:</u> 21 participants with 32 interviews conducted</p> <p><u>Country/setting:</u> Two teaching hospitals in southern Taiwan</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ In-depth semi-structured interview techniques were used to encourage applicants to reflect on their experiences and articulate their feelings. ○ A total of 32 interviews were conducted: 28 face-to-face and four over the telephone. ○ All of the interviews were conducted in Chinese, digitally recorded, and transcribed for analysis. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Data analyzed using inductive analytic approaches to capture patterns in women's responses and generate interpretive descriptions of the phenomena of stillbirth recovery. ○ To establish the dependability and confirmability of the data, two researchers checked the data quality for bias and checked the coding 	<p>Themes:</p> <p>(1) Suffering From Silent Grief</p> <ul style="list-style-type: none"> • Families often did not mention stillbirth after discharge, as if the loss never happened • The avoidance led to a deep sense of loneliness. <p>(2) Shattered maternal role</p> <ul style="list-style-type: none"> • Expectations of family role suddenly taken away • Difficult leaving hospital with empty arms • Grief felt surreal <p>(3) Emotional distance between couples</p> <ul style="list-style-type: none"> • Women felt their husbands became impatient and neglected their emotional needs during their grief. 	<p><u>Strength of Design:</u> Strong</p> <p><u>Quality:</u> Moderate</p> <p>Issues:</p> <ul style="list-style-type: none"> • Interviews transcribed from Chinese to English, potential for misinformation translation. • The researchers do not locate themselves culturally or theoretically.

Study/Design	Methods	Key Results	Comments
<p><u>Authors:</u> Vivekananda et al. (2023)</p> <p><u>Design:</u> An explanatory mixed-methods design was adopted to capture the experiences of bereavement photographers.</p> <p><u>Purpose:</u> to capture the impact of volunteering on Post Traumatic Growth (PTG) in the context of volunteer bereavement photographers' own losses.</p>	<p><u>N:</u> 300 photographers who are currently volunteering for the organization, a final sample of 141 photographers.</p> <p><u>Country/setting:</u> A large, volunteer organization in Australia and New Zealand</p> <p><u>Data collection and outcomes:</u></p> <ul style="list-style-type: none"> ○ The two phases: an online survey and an optional telephone interview. ○ Interviews were conducted by registered psychologists in their graduate studies. ○ Digitally audio-recorded and transcribed verbatim. <p><u>Analysis:</u></p> <ul style="list-style-type: none"> ○ Responses to the four interview questions were transcribed verbatim using Otter (a speech transcription application). ○ Initially two researchers independently coded the data to ensure consistency with discrepancies resolved by the first author. 	<p>Quantitative Findings:</p> <p>(1) Impact of personal experience of perinatal loss on PTG</p> <ul style="list-style-type: none"> • An independent sample t test on PTS scores indicates a significant difference between photographers with a previous perinatal loss (p=0.012). <p>(2) Association between previous loss and PTG</p> <ul style="list-style-type: none"> • The relationship between the number of losses and the PTG scores was a positive relationship (p <0.001). <p>Qualitative Findings:</p> <p>(1) Enhanced understanding of perinatal loss</p> <ul style="list-style-type: none"> • photographers consistently reported that their volunteering work with bereaved parents had substantially altered their viewpoint about perinatal loss and grief <p>(2) Develop effective coping skills:</p> <ul style="list-style-type: none"> • Photographers repeatedly reported how their volunteering had cultivated their resilience and coping skills. 	<p><u>Strength of Design:</u> Moderate</p> <p><u>Quality:</u> Medium</p> <p>Issues:</p> <ul style="list-style-type: none"> • Response rate only 54%, with 20 photographers removed as they did not complete survey, disregarding single responses. • Self-report surveys have a chance of social desirability biases and the PTG scores may be inflated. • The researchers do not locate themselves culturally or theoretically.

Appendix C: Consultations and Environmental Scan Report

Perinatal loss is an umbrella term that includes miscarriage, stillbirth, and neonatal death (Evans et al., 2022; Roberts et al., 2021), and includes termination of pregnancy due to fetal anomaly (Lu, 2022). Women and families go through the same stages of grief as an unplanned pregnancy loss when they choose to terminate (Evans et al., 2022). When a fetus is found to have a congenital anomaly, parents voice mourning the loss of the “normal” healthy baby they envisioned and dreamed of for the future (PHAC, 2022; Power et al., 2022). When a fetus is found to have a congenital anomaly, congenital disability, congenital disorder, or a congenital malformation, it is overwhelming to families when deciding to terminate a pregnancy (PHAC, 2022; Power et al., 2022). Therefore, through discussions with my colleagues, for my practicum project, I chose to develop a patient resource manual (PRM) for women and families after they have made the decision to terminate. Specifically, I chose to create an educational resource for patients undergoing pregnancy terminations for a fetal anomaly. With enhanced education, women and families will be better supported throughout this process.

According to Roberts et al. (2021), enhanced support for women and families leads to better outcomes in terms of lessening traumatic experiences and mental health illness development. The WHIU psychologist, two senior registered nurses (RNs), two novice RNs, and one patient with a history of perinatal loss agree that a PRM could benefit women and families beginning the termination process. Specifically, a knowledge gap exists before the termination process when women and families do not receive enough education surrounding the steps to come throughout the labour process, which may lead to an unnecessary increase in patient suffering (Roberts et al., 2021).

To complete this project, I conducted a literature review to explore the prevalence of perinatal loss and the bereavement process after unexpected terminations of pregnancy.

Specifically, during my literature review, I explored nursing practice and patient outcomes after suffering a perinatal loss. While reviewing the literature surrounding pregnancy termination and fetal anomalies, I found minimal research investigating the benefits of providing a structured termination resource. Of the limited literature I reviewed, the aim of most information offered to women and families suffering a perinatal loss was retroactive, as the majority of research studies explored knowledge and tools provided to women and families after the perinatal loss, as opposed to proactively, before the termination. According to Lu (2022), when women and families are provided with extra support during the termination process, the experience is perceived as less traumatic.

Along with the literature review, I also conducted an environmental scan as well as consultations with local key stakeholders. For quality improvement programs, an environmental scan can be used when widespread data collection is required to achieve a strong understanding of the external environments of existing health programs (Praxie, 2022; Wilburn et al., 2016). For this project, an environmental scan offered the opportunity to explore resources in other geographical areas (Wilburn et al., 2016). Due to the proximity of my institution and time limitations of the semester, I narrowed down my environmental scan to include other select geographical locations within Newfoundland and Labrador (NL) Health Services (NLHS), such as the James Paton Regional Health Centre in Gander, the Central Newfoundland Regional Health Centre in Grand Falls-Winsor, the Western Memorial Regional Hospital in Corner Brook, and the Labrador Health Centre in Happy Valley-Goose Bay. I also chose to scan Athena Health Centre (AHC). The AHC provides medical care, including abortion, to pregnant individuals in an environment of respect and dignity with a focus on reproductive freedom (Thrive, 2023). I selected two facilities in other geographical locations in Canada: The IWK Hospital in Nova

Scotia and The Hospital for Sick Children (SickKids) in Toronto. The IWK is the largest institution offering women's health geographically closest to NL, with 4,498 babies delivered from April 2018 to March 2019 (IWK Health Centre - IWK Health, 2023) and SickKids in Toronto is a tertiary care centre providing family-centered care to children (The Hospital for Sick Children (SickKids), 2022).

Consultations with key local stakeholders are important because, for a change in practice to be successfully adopted by a group of people, the group of people must perceive the idea as transformational (LaMorte, 2022). To develop a successful PRM, consultations with local key holders were integral to determine how consistent the idea for a PRM is with the potential adopters' values, experiences, and needs (LaMorte, 2022). For this reason, I consulted with the WHIU psychologist, two senior registered nurses (RNs), two novice RNs, and one patient with a history of perinatal loss. In this report, I will provide an overview of the findings of both the environmental scan and the consultations and the implications for the development of a PRM for women and families undergoing terminations for fetal anomaly. All consultees agreed that a resource is warranted and should be provided to women and families *before* beginning the termination process rather than after the process.

Methods

I created a consultation and environmental scan plan with detailed objectives, setting and sample, data collection, data management and analysis plan in consultation with my supervisor. Measures to ensure ethical considerations were addressed before beginning this process.

Environmental Scan

The overall goal of the environment scan was to gain information regarding the content as well as the mode of delivery for the PRM development. Specifically, I sought resources supporting women and families before, during, or after planned termination. Through this process, I collected tacit knowledge of information and resources provided to families suffering perinatal losses in Canada. I searched for an educational tool provided to patients explaining the termination process. I also searched for any information/support provided to women before or after a perinatal loss. The objectives of my environmental scan were to:

- Identify examples of written literature, such as policies or resources provided to patients experiencing termination of pregnancy in other jurisdictions, i.e., rural NLHS, the AHC, SickKids, and IWK.
- Determine which consults or follow-ups are offered to perinatal bereavement patients in other jurisdictions.
- Identify examples of written literature from private clinics, such as the Athena Health Centre, to patients experiencing early pregnancy terminations.
- Determine if the Society of Obstetricians and Gynecologists of Canada (SOGC) has any available written literature or resources for pregnancy loss on the internet.

Data Collection

In the following sections, I will describe the process of how I collected data in the environmental scan.

NLHS

I began my environmental scan by identifying four rural sites of NLHS and searching the IWK, SickKids, and AHC websites to locate any email addresses to send an invitation email (Appendix B) to inquire if a resource like my proposed project existed. The aim of my environmental scan was to determine the content to be incorporated in the PRM, as well as the ideal mode of delivery. I met with the manager of the WHIU, who assisted me with collecting the contact email addresses of clinical educators at the four rural sites within NLHS. Once this email list was retrieved, I sent an invitation email to each educator via my professional NLHS email address. This method of communication allowed time flexibility of responses given the surgery slowdown and summer holidays. I therefore expected that there might be a time delay in responses. In the email, I inquired if a resource existed and if it could be shared with me. I received limited responses. The educator from the Western rural site sent some policies for caring for a stillborn and using a cuddle cot. The cuddle cot is used after the delivery of a stillborn to preserve the baby if the family desires for the body to remain with them. However, these policies already exist within the Eastern region as we, as RNs, practice caring for stillborn babies and the operation of the cuddle cot. This information is still valuable to developing my PRM because explanations of the cuddle cot and the care of a stillborn will assist with constructing of the information within the manual.

Local Health Center

I completed a scan of the AHC website and found a general inquiry email in their directory. Their website includes references to printed handouts with relevant post-operative information available to their patients (Thrive, 2023). Using my university email, I sent my

invitation email to their general inquiry email requesting existing resources. After one week and waiting for a response, I sent a follow-up email with no response.

Other Canadian Institutions

My next step was to send the email to the Bereavement Coordinator of the IWK. To send the invitation email, I called the phone number listed on their website, inviting them to send an email to my university email address left on their voicemail system because no email addresses were available on the IWK website. My voicemail to the IWK coordinator included a brief overview of my project and the purpose of this environmental scan. I explained the information I was looking for and left my email address on the voice recording for the coordinator to follow up with my request. The IWK coordinator sent me an email very quickly. This email included links to their online patient resources for pregnancy termination preparation, as well as some information surrounding their hospital admission process. Contact information for two IWK social workers responsible for perinatal loss was also included in the email from the IWK coordinator.

I completed a scan of SickKids' website by searching bereavement in the directory on their website. I located a Grief Support Coordinator, Pediatric Advanced Care Team (PACT), and Pathways Grief Support Program, all of which included an email address. I sent the invitation email to each of these three email addresses on the SickKids website. After one week with no response, a follow-up email was sent with no response.

I used a business-based approach taken by Praxie (2022) to organize the information from the environmental scan. Praxie (2022) categorizes information on a topic within political, economic, social, technological, and patient focus themes. This method promotes grouping

information into political factors impacting the PRM, economic factors related to the financial constraints for bereavement support, social factors relating to women and families and perinatal loss, with technological factors and resources for perinatal loss support. Lastly, following Praxie (2022), I described patient-related factors such as patients' expectations, needs, and wishes.

Consultations

While completing my environmental scan, I concurrently completed consultations with internal members of the WHIU and one past patient. The overall goal of the consultations was to gather locally relevant information from members of the WHIU and other healthcare members employed with the healthcare authority involved in the termination/bereavement process. I also consulted an advocate in the community for perinatal loss support and policy change. As a result of their experience of the termination process, they advocate for the recognition and changes in policies surrounding perinatal loss. The objectives for my consultations included:

- Create an interview guide for face-to-face interviews with local key stakeholders
- Select, schedule, and conduct semi-structured face-to-face interviews with staff RNs. I will utilize the same semi-structured guide for the face-to-face interviews with all staff RNs chosen.
- Select, schedule, and conduct semi-structured face-to-face interviews with the social worker and the psychologist to examine available bereavement support and ideas for resource development.
- Select, schedule, and conduct semi-structured face-to-face or zoom interview with a previous patient to explore available bereavement support and the support needs.
- Analyze data from all face-to-face interviews to assemble common themes and ideas.

The past patient consultation was not a part of the initial plan. I modified the plan to include this person, as they are an advocate for perinatal loss support and policy change, advocating for better maternal healthcare for women experiencing perinatal loss. I modified my objectives to include this person as it was important that I include a voice from the patient's perspective. Because the past patient is already involved in improving bereavement care, I was able to reach out to their email address. The email explained the purpose and aim of my practicum project to invite them to a consultation with the information sheet attached.

Data Collection

Over a two-week period in July 2023, I scheduled semi-structured face-to-face interviews with the WHIU psychologist, the WHIU social worker, two senior RNs, two novice RNs on the WHIU, and one past patient. My pre-developed interview questions guided the face-to-face interviews (Appendix D). This guide included open-ended questions with opportunities for consultees to add any additional information they felt was important to the topic. Open-ended questions assisted with gathering more detail through handwritten field notes during the interview and detailed reflections immediately following each consultee encounter (Crossman, 2021). During the consultations, we discussed resource content and how the information should be provided to patients and families. At the end of each interview, I ended with an opportunity for comments, questions, concerns, or any other information the consultee felt was necessary.

Due to the past patient's known involvement in bereavement care, I felt it was appropriate to reach out for a face-to-face discussion for their input on the resource development. I asked similar open-ended questions to this individual as to the internal consultees of the WHIU, guided by the questionnaire in Appendix D. I sought to gain insight into the perceptions of a former patient regarding the content and mode of delivery of the PRM. This information is

integral in the development of the PRM, as the past patient has personally experienced planned termination and thus can provide an insider's perspective on information and support that is needed by women and families.

Ethics

This project is exempt from Health Research Ethics Board approval as quality assurance and quality improvement studies, program evaluation activities, performance reviews, and testing within normal educational requirements, if there is no research question involved (used exclusively for assessment, management or improvement purposes), are exempt (Appendix A). This project is a quality improvement project within an educational program. Additionally, the internal email used for the environmental scan of other areas within NLHS, the email system requires a two-step authentication to access, allowing for improved privacy and data protection. There was no audio recording during any of the consultations, whether by virtual platform or face-to-face. I took notes during the consultations and transferred the notes to a Microsoft document stored on a password-protected computer with up-to-date spy-ware.

Data Management

Using the approach by Praxie (2022) for the environmental scan, I organized the information received from rural NLHS, the AHC, SickKids, and IWK based on political, economic, social, technological, or patient influence. I kept this information in a password-protected Microsoft Word document on a password-protected computer.

During the consultation interviews, I took handwritten notes directly onto a printed copy of my interview guide and then transcribed the notes into a Microsoft document immediately after each consultation. This transcription occurred as soon as possible to ensure an accurate

recollection of the face-to-face interviews (Crossman, 2021). After transcription, I reviewed the notes to familiarize myself with the data and refresh my recollection to update any missing information. The Microsoft document was password-protected and kept on a password-protected computer.

Data Analysis

Using Bengtsson's (2016) qualitative content analysis method, I familiarized myself with all the collected information by reviewing each document several times. Using this method, I considered the data and formed conceptualizations in four main stages: decontextualization, recontextualization, categorization, and the assembling of similar themes/groupings (Bengtsson, 2016). I pooled the data into categories and developed final themes into separate tables (Appendix F). Using content analysis to examine social phenomena is non-invasive, instead of stimulating social experiences to collect questionnaire feedback (Paradis et al., 2016). Examining the viewpoints of diverse consultees allowed for highlighting similarities and differences and generating insights from different healthcare professionals. Capturing as much data as possible allows all phenomena elements to come together to create common themes from all data collection methods, including the environmental scan, consultations and the literature review (Sandelowski, 2000). In the next section, I will discuss the findings from the environmental scan and the consultations, including implications for developing the PRM.

Findings

Environmental Scan

I received a limited number of responses to my invitation emails. Locally, the clinical educator in GFW responded to inform me that terminations of pregnancy due to a fetal anomaly

do not occur outside St. John's. Rural women and families are required to travel to St. John's for terminations or avail of a limited mobile clinic which travels around the province of NL. I received a response from the Western region of NL, which included policies already available at the Eastern Region. No other responses were received within NLHS. Of the three contacts from SickKids in Toronto that I contacted, only the grief support coordinator responded to my email, explaining that they were short-staffed at this moment in time and did not provide any resources or information.

The Bereavement Coordinator at the IWK responded to my voicemail rather quickly. I received an email from the IWK Coordinator with weblinks to various pertinent resources for termination of pregnancy, including: "*Methotrexate for Ectopic Pregnancy*," "*Taking Mifepristone for Pregnancy Termination*," "*Early Pregnancy Loss: A Patient Guide to Treatment*," "*Information & Resources to Support you During Pregnancy Loss*," and "*Managing Your Breast Milk after the Loss of Your Baby: A Guide for Bereaved Parents & Families*." These are important for developing my PRM because they include information for women and families who must terminate about what to expect before admission to the hospital. Further, I can adapt this resource for the local context as it includes what to expect at home taking the first medication of the termination process. The resource also includes a brief overview of what to expect in the hospital. Organized according to Praxie (2022), the IWK Coordinator highlighted social factors such as miscommunication that impact termination management and offering each resource at the IWK in French, Arabic, and Chinese. They are currently working on expanding the resources into more languages. The IWK Coordinator also discussed physical book resources provided to women and families by their PACT, including storybooks on death and grief for children, workbooks or journals on grief, self-help books for

adults on grief, etc., as the technological resources they offer for the management of termination of pregnancy. The IWK Coordinator also connected me with two social workers who primarily work with pregnancy loss under and over 22 weeks' gestation. I received no response from either social worker. After one week, I resent the invitation email and did not receive a response.

In summary, I organized the findings from the environmental scan according to Praxie (2022). These are political factors (women and families outside the metro region of St. John's, NL must travel to the WHIU for termination of pregnancy. For example, a woman from St. Anthony, NL must take time off work and potentially lose income to travel, with their spouse who could also potentially lose income from time away from work), cultural factors (cultural practices may include many different rituals, and a further understanding of each individualized culture should be taken into consideration for the PRM construction, termination seen as tabu), economic factors (leaving rural NL for termination adds economic stress of accommodations and travel expenses on top of the already traumatic experience, as well a medication is often given in the community 24 hours before admission, insurance coverage), technological (web-based patient resource can be accessed province wide depending on the geographical location in which the woman and family requiring termination resides) and patient (including preferences and expectations; the IWK resource includes the process of misoprostol tablet insertion and what to expect with administration).

Consultations

The themes that emerged from a synthesis of findings from the consultations were: understanding information, preparation before the termination is ideal, a web-based resource is better suited for this generation, the termination process should be described, and medical language terms may not accurately depict the labour process. Due to time constraints, the WHIU

social worker was off on summer holidays, so consultation did not occur with this individual. During the developmental phase of the PRM in N6661, it is important that I contact this individual to validate the content of the PRM.

More Information Improves Understanding

Consultees reported that a PRM can be helpful for most women and families. When presented with more information, improved understanding helps with the coping with traumatic grief and may lessen the experience of that grief. For some women and families, more information can cause them to feel overwhelmed. A consultee reported that if women and families feel overwhelmed by more information, they can choose not to view some or all the PRM.

Preparation Before the Termination is Ideal

Most stakeholders report that the PRM should be provided as reading material in preparation before admission to the hospital. Preparation and additional support provided to women and families before beginning the termination assists with expectations prior to experiencing the termination procedure. Novice RNs were the only local stakeholders who reported feeling unprepared for the bereavement process from a nursing care point-of-view, with 100% of those consulted expressing a lack of confidence in the supportive role of the bereavement process. With this lack of confidence and experience, 100% of novice RNs said the PRM should be provided to women and families on admission to the hospital so that the RN can learn along with the patient and answer questions with women and families. While the novice RNs' lack of experience may contribute to this finding, it is important to note the difference

between novice RNs and the other key local stakeholders. Most local key stakeholders desire the PRM before hospital admission.

Mode of Delivery

Most stakeholders reported that a web-based resource is ideal for this population of patients. However, with written material, women and families can have more control over how much literature they take in. Another consultee reported that using web-based resources is ideal for the generation of patients, with most women of childbearing age being tech-savvy. Most consultees say a website link would be the perfect mode of delivery, with minimal consultees preferring a booklet. During the consultations, I found that providing the PRM as a booklet before admission may assist with reaching more applicable women and families undergoing termination of pregnancy. By having the PRM as a written booklet, the population of patients who do not have access to a computer will not be at a disadvantage.

Included Content

Local stakeholders reported that it is important to include information about the medical procedure in the resource. Most RN consultees think the PRM should include the step-for-step process of medical termination in the PRM. A small percentage of the consultees believe the step-for-step process could be too overwhelming and lead to unnecessary pre-admission stress. However, 80% of consultees believe the PRM should include the step-for-step process. Similarly, Kalanlar (2018) acknowledged the benefits of providing step-for-step instructions to women and families facing unexpected, planned terminations. Further, the PRM should include explanations of all people involved in the termination process and their professional contact

information to allow women and families to contact them with any questions/or concerns prior to admission.

Consultees reported that the unexpected condition of the fetus at delivery, such as the colour and appearance of the skin, caused the most stress for women and their families. The PRM could inform potential termination patients of what to expect with the appearance of the fetus, assisting them with the informed decision to view the fetus at birth.

Medical Language Terms May Not Accurately Depict the Labour Process

Consultees suggested that the term miscarriage is confusing to women and families as it does not accurately depict the steps of labour to come. More open information on labour stimulation is warranted, and all information should be provided in plain language. All consultees disclosed that the PRM should include where the termination will occur, along with visiting rules and unit policies explained in simplified terms and direction.

Implications of Findings

The information found during consultations and the environmental scan is consistent with the literature. Including the step-for-step termination process is desired, as well as what to expect regarding the baby's appearance are important to be included in the PRM content. Having completed the environmental scan and the consultations, the implications of these findings for the development of my resource suggest the mode of delivery of the PRM should be in booklet form to reach all women and families undergoing termination of pregnancy regardless of their financial state and access to the internet and computer. Additionally, a written resource in booklet form can assist with limiting the amount of information the family unit takes in, as they can choose to reach as much or as little as they feel is necessary. The booklet will be ideally

given to women and families *before* the termination process, providing more information to assist with the traumatic experience.

Facilitators and Barriers

Environmental Scan

During the environmental scan, there were facilitators and barriers to data collection. The IWK provided web-based access to patient guides for the termination process. The personalized voicemail left on the IWK's bereavement coordinator's voicemail can be considered a facilitator in accessing information. I was unable to obtain an email address to send my invitation email to the bereavement coordinator, so I used the telephone number provided and was prompted to leave a voice memo. I believe the voicemail encouraged the consultee to respond. The IWK bereavement coordinator provided me with many resources and a detailed lengthy explanation of their process for termination of pregnancy.

Barriers to my environmental scan include the timing of the semester. During summer months, to facilitate holidays, there are many health care slowdowns, such as a decrease in the number of surgical procedures, and many people are away from the workplace for extended periods. I think due to timing, many emails sent for the environmental scan were left unanswered as people are away from the workplace, hindering the collection of data from my environmental scan. SickKids in Toronto responded to my inquiry, however expressed their short staffing at the exact moment and referred me to another department for a response, which I did not receive.

I received few responses from the contacts at other healthcare facilities in NL. I think this is because I did not know any of the identified clinical educators personally, and they may have had no relevance to the development of my resource. Most congenital anomalies are referred to

the Janeway Children's Hospital for a more in-depth diagnosis through the Maternal Fetal Assessment Unit (MFAU) before confirmation. Because of this, many of the rural sites within NLHS may not face the termination of pregnancy due to fetal anomaly. In hindsight, I could have contacted other Atlantic provinces for my environmental scan to collect more data surrounding termination of pregnancy by choice, rather than because of a congenital anomaly because there may be a broader range of information surrounding pregnancy termination. With my success of a response from the IWK, I think a phone call to all consultees within NLHS, AHC and SickKids requesting my desired information might have yielded more results.

Consultations

I retrieved more robust data in the consultations than the environmental scan. The main reason for this is that most consultees were my coworkers at the WHIU. By knowing the consultees personally, I collected more valuable data as the personalization of the consultations may have increased their willingness to contribute. The nature of the topic is of interest to all consultees, as these individuals had previously identified a knowledge gap in this area. Furthermore, seeing my consultees in the workplace was a frequent reminder to complete the face-to-face consultations.

Another facilitator for the consultations is the flexibility to conduct them during work hours. Many consultees have busy lives outside of the workplace, making scheduling face-to-face meetings difficult on personal time. Due to the semi-formal nature of my consultations, many of them could occur during the workday, in casual conversation or leisurely in the breakroom. With this flexibility, I could pause a consultation and resume at a later convenient time if necessary.

A barrier to completing my consultations was the timing of the semester. Consultation with the WHIU social worker did not occur due to summer vacation. Additionally, the spring and summer months typically have an increase in the patient census, often at full capacity (RN, personal communication, June 2023). This makes the unit very busy as our staffing ratios only account for a 75% occupancy (RN, personal communication, June 2023). While considered a facilitator, knowing the consultees can be seen as a barrier. Having a personal relationship with the consultees can introduce bias. The consultees may have provided feedback surrounding the mode of delivery and content to match what I desire or have previously discussed in leisure conversation on the WHIU. The literature review was completed first to get an overview of whether this resource may be needed and the benefits of such resources and to gather an overview of whether this resource is needed. My literature review demonstrated the benefits of such resource before I moved on to explore local factors through my environmental scan and consultations. Because of a position vacancy, I was unable to meet with the WHIU social worker. The input from this individual is integral to the PRM, and therefore I plan to meet with the WHIU's social worker during PRM construction.

Conclusion

During the environmental scans and consultations, I aimed to gather information to develop a PRM for women and families undergoing a termination of pregnancy due to a fetal anomaly. I contacted four rural facilities within the NLHS and two other facilities in Canada. I found that pregnancy terminations for fetal anomaly often do not occur outside St. John's, NL. The IWK provides an online patient resource for women and families prior to admission to hospital, prior to termination. I can adapt aspects of this resource when developing my PRM because the resource includes information surrounding what to expect for the 24 hours while at

home, as well as some information regarding admission to hospital. Consultations with members of the WHIU occurred locally, and I developed five themes. The timing of my data collection could have impacted the amount of information found with numerous efforts to connect with consultees and facilities of interest during the prime summer holidays. Together, the information obtained from the environmental scan and the consultations will assist with developing the content for the PRM and the mode of delivery. I will include information from the IWK patient resource for termination of pregnancy before hospital admission and will deliver it via a printed booklet.

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Health Research Ethics Authority (HREA) Screening Tool

Student Name: Ashley Greene

Title of Practicum Project: Creation of a Patient Resource Manual for the Bereavement Process for Unexpected Termination of Pregnancies

Date Checklist Completed: June 15th, 2023

This project is exempt from Health Research Ethics Board approval because it matches item number three from the list below.

1. Research that relies exclusively on publicly available information when the information is legally accessible to the public and appropriately protected by law; or the information is publicly accessible and there is no reasonable expectation of privacy.
2. Research involving naturalistic observation in public places (where it does not involve any intervention staged by the researcher, or direct interaction with the individual or groups; individuals or groups targeted for observation have no reasonable expectation of privacy; and any dissemination of research results does not allow identification of specific individuals).
3. Quality assurance and quality improvement studies, program evaluation activities, performance reviews, and testing within normal educational requirements if there is no research question involved (used exclusively for assessment, management or improvement purposes).
4. Research based on review of published/publicly reported literature.
5. Research exclusively involving secondary use of anonymous information or anonymous human biological materials, so long as the process of data linkage or recording or dissemination of results does not generate identifiable information.
6. Research based solely on the researcher's personal reflections and self-observation (e.g. auto-ethnography).
7. Case reports.
8. Creative practice activities (where an artist makes or interprets a work or works of art).

For more information, please visit the Health Research Ethics Authority (HREA) at <https://rpresources.mun.ca/triage/is-your-project-exempt-from-review/>

Draft Environmental Scan Email

Hello [name],

My name is Ashley Greene. I am a Master of Science in nursing student at Memorial University in Newfoundland, Faculty of Nursing and am in the final year of my program. As part of my last practicum, I am developing a resource manual for patients undergoing a termination of pregnancy due to a congenital anomaly. As part of this resource development, I am conducting an environmental scan of other health regions in NL as well as Canada. I am contacting your institution to inquire about the following:

- Is there a resource(s) for patients undergoing a termination of pregnancy because of a fetal anomaly at your institution? This could be pre, intra or post-procedure information.
- If yes, could you please provide me with a copy of this resource or directions to where I could attain the resource, if locally available?

I appreciate your time in advance for sharing this information. If you prefer, we could discuss the above questions via phone or virtual platform at your convenience. I look forward to hearing from you.

Best regards,

Ashley Greene BN RN

MScN Student

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709-728-5121

Draft Consultation Information Email

Hello,

My name is Ashley Greene, and I am a registered nurse (RN) on the Women's Health Inpatient Unit (WHIU). I am a Master of Science in nursing student at Memorial University Faculty of Nursing, and I am completing my final practicum project. I am interested in developing a resource for our patients and families undergoing the termination process. I have identified a knowledge gap with our patients arriving at the WHIU for termination with minimal knowledge of the steps to come. I am interested in your point of view for the development of the resource, specifically content and mode of delivery of the resource.

I am inviting you to a face-to-face discussion (or via Zoom) at your convenience regarding your opinions and feedback on developing a patient resource manual for terminations, specifically for women undergoing an unexpected termination for a fetal anomaly. Please take your time to read the following information and reach out to me if you have any further questions.

To maintain confidentiality and anonymity of my consultations, I will not use any identifying information. I will use assigned letters at random (A, B, C, etc.). No audio recording will occur, as I will take short-formed notes during the face-to-face interview. Information will be stored on a spy-wear secure password-protected email, requiring a daily two-step authorization with a phone number to verify to ensure protection of valuable interview information.

Thank you and I look forward to hearing from you.

Kind regards,

Ashley Greene (Owens) BNRN

MScN Student

709-728-5121

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Dr. Renee Crossman PhD BNRN

crossman@mun.ca

Questionnaire

(1) Do you think the information bereavement patients receive before beginning the termination of the pregnancy process is enough? Can you explain?

(2) Do you think a patient resource manual (PRM) would be helpful if provided to clients who must undergo an unexpected termination of pregnancy? Can you explain?

(3) When do you think the manual should be provided and why?

(4) What do you think the manual should include? What education and/or information should be provided?

(5) How do you think the manual should be delivered? (i.e, pamphlets, videos, etc.)?

(6) Do you have any other comments?

Environmental Scan Findings

Environmental Scanning	Example	Information Retrieved/Themes
Political	Issues and common themes regarding termination of pregnancy from political standpoint	<ul style="list-style-type: none"> ○ Women and families outside the metro region of St. John's, NL must travel to the WHIU for termination of pregnancy. For example, a woman from St. Anthony, NL must take time off work and potentially lose income to travel, with their spouse who could also potentially lose income from time away from work. ○ The mobile clinic is offered semi-annually only, leaving women and families in rural NL at a disadvantage of not being able to obtain the healthcare they require in their geographical location for termination of pregnancy.
Economic	Factors such as health care system, personal finances, and healthcare access	<ul style="list-style-type: none"> ○ St. John's the only location in NL offering termination of pregnancies for fetal anomaly. Leaving rural NL for termination adds economic stress of accommodations and travel expenses on top of the already traumatic experience. ○ Medication coverage and insurance plans. A medication is often given in the community before 24 hours before admission. Affordability?
Social	Cultural and social factors that impact termination management	<ul style="list-style-type: none"> ○ Pregnancy termination may be viewed as taboo by different cultures ○ Culture affects parents' reactions, decision-making, coping mechanisms, and the support available from others when a baby is stillborn. ○ Cultural practices may include many different rituals, and a further understanding of each individualized culture should be taken into consideration for the PRM construction. ○ The IWK Coordinator emphasized that each resource is available in French, Arabic, and Chinese. ○ The IWK identifies in their resource that the hospital chaplain or a representative of the applicable faith can hold a short service or say a prayer for your baby after delivery.

Technological	Technological resources or developments for the management of termination of pregnancy	<ul style="list-style-type: none"> ○ Web-based resources are ideal for delivery of health information ○ A web-based patient resource can be accessed province wide depending on the geographical location in which the woman and family requiring termination resides. ○ The IWK offers physical book resources to women and families by their PACT, including storybooks on death and grief for children, workbooks or journals on grief, self-help books for adults on grief.
Patient	Patient preferences, needs, desires, and expectations	<ul style="list-style-type: none"> ○ The IWK resource provides what to expect when using medical management for termination of pregnancy, as well as common side effects. ○ The IWK resource also includes the process of misoprostol tablet insertion and what to expect with administration. ○ Pain medication options are also provided by the IWK resource

Component of Analysis	Meaning	Condensed Meaning	Theme
<i>Knowledge</i>	<ul style="list-style-type: none"> ○ Being well informed can lessen suffering. ○ More information of the steps of the termination experience may lessen the traumatic experience. 	Improved coping	Preparation for termination of pregnancy before the termination is ideal.
<i>Timing</i>	<ul style="list-style-type: none"> ○ Providing information prior to termination can lessen the traumatic experience by preparing each woman and family on what to expect. ○ What to expect, appearance of baby at delivery. 		
<i>Language Use</i>	<ul style="list-style-type: none"> ○ Medical term miscarriage does not accurately depict the termination process and labour stimulation. ○ All information should be provided in plain language. 		

Appendix D: Patient Resource Manual



(Northwest Community Healthcare, 2023)

**Termination of Pregnancy for Fetal Anomaly:
A Patient Guide to Treatment for Patients and Families**

Developed By:

Ashley Greene (Owens) BNRN

MScN Student



Adapted from the
IWK (2021) Patient
Guide: Taking
Mifepristone and
Misoprostol for
Pregnancy Termination



www.iwk.nshealth.ca

The distance between joy and sorrow can be measured by a heartbeat.

Just one heartbeat later you learn something is wrong.



(Gundersen Health System, 2023)

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Part One: Before Admission to Hospital



1.1 Diagnosis of Fetal Anomaly

You have been given this manual because termination of your pregnancy is required. You may have been diagnosed with a fetal anomaly during your anatomy scan between 18- and 20 weeks' gestation, or you have presented to the emergency department with pregnancy complications detecting a loss of fetal heartbeat or a halt in fetal growth for various reasons (Kose, 2015). Due to the later gestation of your pregnancy, admission to the hospital is needed for your pregnancy termination. The admission will require induction of labour and delivery of the baby. The admission is at least a one-night hospital stay.



Losing a baby is difficult. It is a shock to realize that your hopes and dreams for your baby cannot happen in the way you have been dreaming of. The birth of a baby is usually a joyous occasion. When the outcome of a pregnancy is not the one hoped for, people can feel devastated. It is a loss. Grief from perinatal loss is unique because parents do not have the same opportunity to make memories with their children. The aim of this manual is to prepare you for the termination process by informing you and your family of the steps to follow while also offering you and your family a chance to make decisions for special memories with your child.



(Eastern Health, 2023)

Your choices are not right or wrong through this termination and bereavement process. Let your heart and feelings guide how you express your needs during the termination. Even with a thoroughly planned goodbye, the pain will not disappear. Remember, you will still grieve with the best hello and goodbye you can give (Gundersen Health System, 2023). This manual is designed to assist with the grieving process by outlining the process for termination as well as

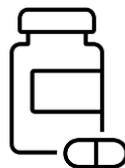
available supports both during and after termination. You are not alone, and the hope is with preparation of the termination process, your experience will be less distressing.

1.2 Taking Mifepristone for Pregnancy Termination

Before admission to hospital for the termination of pregnancy, you will receive a prescription for Mifepristone (Mifeprex®).

What is this pill?

- This medication prepares your cervix for labour and helps your uterus respond to Misoprostol (Cytotec®) (this medication is explained more later and is given in hospital). Mifepristone (Mifeprex®) is a medication used for treatment of Cushing's syndrome and uterine leiomyomas. The medication stops the supply of hormones that maintains the interior of the uterus supporting pregnancy (Mayo Foundation for Medical Education and Research, 2023).



When do I take this pill?

- Mifepristone (Mifeprex®) is taken at home, 24-hours before your admission to the hospital.
- Your care provider will provide specific timing and instructions on when to take this medication at home once arrangements for admission to the hospital is organized.

Please let your doctor know if you:

- are on a blood thinner (anticoagulant) because you are at an increased risk of bleeding.
- have any bleeding conditions or issues with your adrenal glands because Mifepristone increases the amount of circulating cortisol in the blood.
- are taking any steroid medication for asthma as Mifepristone may worsen your condition.
- have had an allergic reaction in the past to either misoprostol or mifepristone.

1.3 What to expect at home after taking Mifepristone (Mifeprex®):

- Most people have no symptoms.
- You can continue with your activities of daily living.
- You may endure light vaginal bleeding, cramping, nausea, or stomach pain.
- If you experience any heavy bleeding (like a menstrual period), severe cramping, or stomach pain, please go to your nearest emergency department for assessment.



(Mayo Foundation for Medical Education and Research, 2023)

1.4 What to expect on arrival to hospital:



(Eastern Health, 2021)

- Twenty-four hours after you have taken your dose of Mifepristone (Mifeprex®), you will present to the admitting department of the Health Science Centre Complex (your first left in through the main entrance, also known as the yellow brick road). If it is late at night or a weekend and the department is closed, please present to the Women’s Health Inpatient Unit (WHIU) on 5 North B (take the women’s health elevators at the end of the yellow brick road to level five).



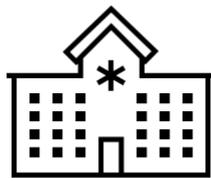
- Please call the nursing unit on 5 North B at 709-777-7422 if need further direction.



- Come to the main nursing station for admission on 5 North B (there is a blue sign above the desk stating “nursing centre”). Someone will come assist you if not already present at the main nursing desk. Instruct them you are here for admission.



- You will be guided to a private room on 5 North B which includes accommodations for your support partner to rest as well. The room will not be charged and will be billed to Newfoundland and Labrador Health Services (NLHS) as a private room for medical reasons.



Part Two: Admission to Hospital

2.1 What happens after you are placed in your patient room:

- Your nurse will come introduce themselves, collect your vital signs, collect a health history, and list of your current medications. Your vital signs will have to be collected every four hours for majority of your admission to hospital.
- A picture of a butterfly/rainbow will be placed on the door of your room. This will symbolize sensitivity and limitation of the number of interruptions including healthcare staff such as dietary and housekeeping.
- You will have to have your blood collected shortly after admission. They will test your blood level prior to beginning labour induction. They will also determine your blood type at the same time in case of any extra bleeding during delivery. This testing will ensure your blood levels are at a safe level in case of any extra bleeding during delivery.
- They may also collect additional genetic bloodwork depending on your reason for termination which can be a longer process and will be collected at the same time as other bloodwork testing.



- Placement of an IV is required as well, in case of extra bleeding, and for medication administration.



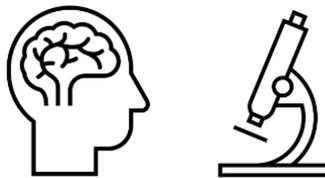
- You will be introduced to the resident physician on call for the day. They will be administering the medication every four hours and assessing cervix dilation. If the resident is unable to arrive for medication administration due to other time sensitive obligations, the medication may be administered orally.



- The resident physician may be present for delivery. A staff Obstetrician is also available if required.

2.2 Medical Examination of the Baby:

- You will be asked by your healthcare provider if you would like an autopsy of the baby. An autopsy can give you and your family information in the case of suspected genetic illness.
- Autopsy may provide answers for future family planning. Hereditary causes are also important information for brothers and sisters, and other family members of the baby who has died. The more complete the medical information available to you and your doctor, the better genetic counseling you will receive.
- Sometimes, knowing the congenital anomaly before termination is enough answers for some families. The decision is yours.
- After the autopsy takes place, the hospital will send the remains to the funeral home. If no autopsy, the hospital will coordinate funeral home transfer, both private funerals and communal burials.
- You may be asked by your healthcare provider to participate in research.



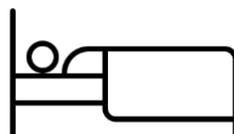
2.3 Starting the stimulation of labour:

- You will be given a pill called Misoprostol (Cytotec®) which in Canada is used for the treatment and prevention of stomach ulcers caused by nonsteroidal anti-inflammatory medications (Chatsis & Frey, 2018). Misoprostol (Cytotec®) also causes smooth muscle stimulation producing uterine contractions with dilation of the cervix and is approved in Canada for the termination of pregnancy (Chatsis & Frey, 2018).

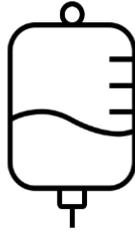


(WebMD, 2023)

- Misoprostol (Cytotec®) will be inserted into your vagina every four to six hours by the resident physician until delivery occurs. The medication generally starts to work about 2 to 6 hours after it is in place.
- You should lie down for 60 minutes after insertion to allow the tablets to start to be absorbed. After an hour you may resume your activities until the labour process begins.



- You may experience vaginal bleeding, which sometimes can be heavy. Heavy bleeding is defined as soaking a pad every hour or more for 3 hours. The nurse will be monitoring your level of bleeding closely.



- The nurse will remain with you once you become in active labour, which can take a varying amount of time depending on individual characteristics, such as a history of previous deliveries. Active labour is when your contractions become regular, occurring every two to three minutes and lasting approximately 45 seconds. You may need a few doses of Misoprostol (Cytotec®) before this happens.



2.4 Pain Management



- There are pain medication options for the management of uterine cramping and contractions. As well, there are medications to treat the side effects of Misoprostol (Cytotec®) including fever, nausea, and diarrhea.
- If you have no health concerns or allergies, some common medications to take are acetaminophen (Tylenol®); ibuprofen (Motrin®, Advil®) or naproxen (Aleve®).
- Acetaminophen (Tylenol®) and a nonsteroidal anti-inflammatory medication such as one of the following: ibuprofen (Motrin®, or Advil®) or naproxen (Aleve®) can be used together. Dosing and frequency of administration of pain medications will be provided during discharge instructions.
- It is important that you do NOT use ASA (Aspirin®) because it may increase your bleeding.
- Do not be alarmed if you need to use a stronger pain medication, such as opioid medication. This is normal for most women. Your doctor may choose to prescribe stronger pain medication to assist with labour progression.



2.5 Preparing for delivery:

- You will be asked if you and your partner want to see your baby after delivery. Babies born around this gestation are often less than one pound. For perspective, babies born <500g are classified as a miscarriage, and >500g is classified as a stillbirth.
- Keep in mind the baby may be dark in colour, or the skin may be shiny because of the early gestation of the baby. Depending on the fetal anomaly, each baby looks different. Be prepared for the baby to not look like a newborn due to the early gestation.



- It is ok if you choose not to see your baby, your nurse can take photographs if you would like to have to take home and view later. Hand and footprints can also be collected.



- A memory folder will be given to you on discharge including all the mementoes, the blanket, and the hat.

2.6 Burial/Funeral arrangements:

- You may opt to arrange your own funeral arrangements. Coordination with a private funeral home of your choosing is needed if this route is chosen.
- If mothers and/or families do not wish to personally arrange a funeral, you may opt for the hospital to take care of the remains. Once a year, the cremated remains are all put together by a local funeral home. Parents are then invited to a burial service, usually scheduled for early summer for all babies that have passed the previous year.
- There is a communal gravesite. The monument is a tear drop located in the Holy Sepulchre Cemetery on Topsail Road in Mount Pearl.



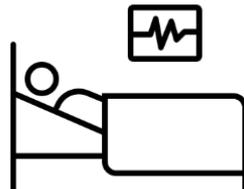
(CBC/Radio-Canada, 2018)

2.7 What to expect during delivery:

- You will stay in the private room on 5 North B for delivery.
- Your nurse will be with you the entire time. The resident physician will come for delivery if able.
- Typically, the cervix must dilate to ten centimeters for a vaginal delivery. Because of the early gestation and small birth weight of your baby, full dilation to ten centimeters may not be required. You may feel like you need to move your bowels prior to delivery with most likely only a few pushes for delivery of the baby.
- Epidurals are not used for pain control. The nurse will administer medication either through your IV, an injection, or by pill form. A Patient-Controlled Anesthesia (PCA) machine may be an option for management of labour pain.
- The nurse will take the baby to the treatment room for assessment, weight, and to be wrapped once born. The nurse will bring the baby back wrapped and with a hat to be held by you and your family, if requested. You can opt for immediate skin-to-skin if you desire.
- The nurse will monitor your bleeding very closely after delivery until the placenta is delivered.
- Your placenta must deliver within four hours after delivery of the baby. If this does not occur, the placenta is considered “stuck”. A Dilation & Curettage (D&C) in the operating room is needed for small number of women (less than 1%) because of a retained placenta or because some pregnancy tissue may not be delivered.

2.8 What is a Dilation & Curettage (D & C):

- For this procedure, you could be put to sleep with general anesthetic; or you could stay awake using medications given intravenously for pain and relaxation called conscious sedation (IWK, 2021).
- The cervix is opened by putting small rods into the cervix (starting with a very small one and increasing the size of each rod) until the cervix is opened (IWK, 2021).
- Once the dilation is accomplished, a plastic suction tube is placed within the uterus attached to a suction machine (IWK, 2021). Gentle suction is used to remove the pregnancy tissue from the uterus. Suctioning often needs to be done more than once to remove all the pregnancy tissue (IWK, 2021).
- The D & C procedure usually takes 10 to 15 minutes
- All tissue removed at the time of D & C is sent to the pathology laboratory for examination.
- After your procedure you will stay in the recovery room for approximately one hour, to make sure your cramping and bleeding have settled. You may have to spend one night in hospital depending on individual bleeding levels.



Part Three: After Discharge

3.1 Discharge instructions:

- Experiencing labour is physically exhausting, get plenty of rest over the next few days.
- Do not take baths or go swimming for 4-6 weeks. This is because where the placenta was attached to the uterus is now a wound inside of you. Taking baths or going swimming increases your risk of an infection.
- Do not put anything inside the vagina for 4-6 week's including tampons. Use sanitary napkins to manage your bleeding. For the same reason as above, this is to prevent infection and assist with healing of the uterus.
- Do not douche or have sexual intercourse for 4-6 weeks to prevent infection.



3.2 Adjusting to the loss of your baby

You may experience feelings of sadness, loneliness, anger, or emptiness after arriving home. It is possible to feel overwhelmed at the thought of seeing pregnant women or your friends who have young children. You may have questions about the physical changes your body is going through such as milk production. Family and friends can be supportive and may understand that you are grieving; however, sometimes people are not sure what to say to offer you comfort and may say things that you do not find helpful (Eastern Health, 2023a).

Eastern Health offers perinatal bereavement counselling. Support can also be accessed through the women's health psychologist or the women's health social worker. Eastern health can provide you with tips on how you and your family can grieve the loss of your child.

3.3 Management of Breastmilk (IWK, 2021)

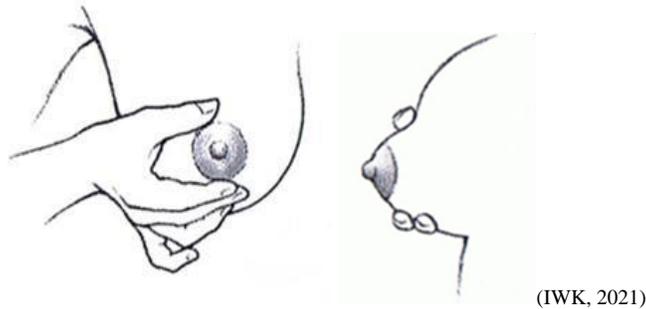
- One of the most difficult times for many bereaved mothers is when their breast milk comes in. Other mothers find the presence of their milk a comforting reminder of their body's ability to care for the baby they so love and miss. Everyone grieves in their own way.



3.4 Hand Expression to facilitate decreasing milk production (IWK, 2021):

- If you want your milk supply to decrease or stop production, it is important to limit pumping and hand expression to just enough to make you feel more comfortable by relieving some of the pressure.
- Hand expression is a way to remove milk from your breasts using gentle compression.
- Place warm towels on your breasts for a few minutes before starting to express.
- Gently massage your breasts toward your nipple and gently roll or tug your nipple. To prevent hurting your nipple, be careful to not squeeze or pull too hard on your nipple.
- Place your thumb and index finger in a C-shape just outside the dark area of your nipple (areola).

- Push back to your chest wall and then gently squeeze and release. To prevent soreness, avoid rubbing or pulling your breast tissue tightly.
- Repeat squeezing and releasing in a rhythmic manner until drops of milk appear. Rotate your hand position around the areola to reach all milk ducts.
- Repeat on your other breast.



3.5 Other comfort measures (IWK, 2021):

- Take a hot shower, letting the water run over your breasts. This may stimulate some milk release and relieve some of the pressure. Or you can sit in a warm bath and lean into the water.
- Wear a supportive bra that does not feel tight or restrict your circulation, many women prefer a sports bra.
- Place cold cabbage leaves inside your bra. The cabbage leaves absorb some of the fluid from the glands within the breast area, reducing the fullness in the tissue.

- Apply ice packs wrapped in a light towel for about 15 to 20 mins several times a day.
You can also use a bag of frozen vegetables such as peas.
- Use medications like ibuprofen and acetaminophen to manage pain and swelling if needed.
- By allowing your milk to flow and decrease naturally, you will reduce the chance of developing blocked ducts. It will also limit your chance of developing mastitis (infection in the breast tissue).

With mastitis, you would: have a tender, reddened area on your breast, feel generally unwell, and you may have a fever. If this happens to you:

- Return to the emergency room with any signs of infection, such as:
 - I. Fever, chills, or sweats.
 - II. Fast beating heart

3.6 A Walk to Remember, St. John's. (Eastern Health, 2023a)

- Each year in October, parents and families who have experienced perinatal loss gather on a designated Sunday afternoon in Bowring Park for a commemorative tree planting ceremony. You will give permission in hospital for the Bereavement Services Program to contact you yearly of the ceremony reminder.
- It is a family-friendly event which includes a short walk through the park.
- This time is set aside for families to offer special acknowledgement for babies who died assisting with the grief process.
- The Walk to Remember is not a fundraiser.

- This event is supported by the Janeway Children's Foundation.
- You do not need to register to attend, you can decide to come last minute.



3.7 After Discharge Contacts

(Eastern Health, 2023a)

i. Social Worker

Children's and Women's Health Program

(709) 777- 7169

A social worker can provide you with different types of counselling and psychotherapy methods, specializing in areas like grief counselling (Canadian Association of Social Workers (CASW), 2023). Social Workers help people to develop coping skills and find effective solutions to their problems and act as liaison for arranging other supports you and your family may need (CASW, 2023).

ii. Pastoral Counsellor

Pastoral Care and Ethics

Bereavement Services

(709) 777-6959

griefandbereavement@easternhealth.ca

Pastoral care is an up-to-date term for a model of emotional, social, and spiritual support that can be found in all cultures and traditions (Eastern Health, 2023). This term is considered inclusive of support for people from religious communities as well as distinctly non-religious forms of support. A pastoral counsellor can provide outpatient grief counselling and coordinates

of commemorative events (Eastern Health, 2023b). Bereavement information, grief support groups, and education can be provided by bereavement services.

iii. Clinical Psychologist

Children's and Women's Health Program

(709) 777-4597

The clinical psychologist will speak to you during your admission. They will introduce themselves provide an overview of the support and resources they are able to provide. Inpatient grief counselling for patients and families is available as well.

3.8 Mending a Broken Heart

Mourning after a loss is the natural way of adjusting to what has happened. It is necessary and healthy to express your feelings, no matter what they are (Gundersen Health System, 2023).

While you may carry elements of grief with you your whole life, the pain now is the most intense and most deep. It will lessen in time (Gundersen Health System, 2023).

You can expect an emotional rollercoaster following the loss of your baby. Most people go up and down, moving through the four phases of mourning (Gundersen Health System, 2023):

- 1) **Shock and Numbness:** Shock is often the first response to tremendous sorrow, and is the most intense in the first two weeks after the loss of your baby. Sometimes it lasts only a few minutes, but often it continues for days. It produces a feeling of numbness, of being shocked, a shutting-down of usual feeling and thinking (Hoag, 2022).
- 2) **Searching and Yearning:** As shock and numbness begin to wear off, the pain becomes more severe and real. These are the signs of commencing the searching and yearning phase of grief. You may explore for answers, crave to experience what could have been, and you may feel empty (Hoag, 2022).
- 3) **Disorientation:** Searching and yearning leads into reality. You have a new sense that life is unfair. Some parents talk of losing their innocence about life and feeling vulnerable in the world. It is a time of ups and downs. (Hoag, 2022).
- 4) **Reorganization and living again:** There comes a time when you need to knowingly let go of your pain. You choose to reorganize, regroup, and get back into your routine. You accept the loss of your baby. You come to terms with what happened and choose to move forward.

This does not happen all at once. There will be diversions, good days, and bad days, but soon more good days than bad (Hoag, 2022).

The phases are not clearly defined. You may experience all the phases at the same time, or one may dominate. You may shift back and forth, even after you thought you had recovered (Gundersen Health System, 2023).



3.9 Additional Supports

(Eastern Health, 2023a)

- a. **Navigating Perinatal Bereavement Video Series** is a three-part video resource provided by Eastern Health (2023a) designed to provide quality bereavement and support services to patients, couples, and their families – regardless of geographic location, availability of suitable counsellors, or time of day. The hope of this video series is to enhance the outpatient grief counselling services provided by Children and Women’s Health, Bereavement Services, and Pastoral Care and Ethics departments.

www.easternhealth.ca “our services” > Pastoral Care > Perinatal Bereavement Series



- b. **Eluna Network** is an organization supporting children and families impacted by grief. The Eluna Network contains a resource centre with many patient resources on what to expect with grief.

<https://elunanetwork.org/>

- c. **“The What’s Your Grief Podcast”** by Eleanor Haley and Litsa Williams.

Instagram: @whatsyourgrief

This is a podcast by the mental health professionals behind the website and book 'What's Your Grief'. They have an 85-episode podcast of topics ranging from grief theory to coping. Listeners will find their approach practical, relatable, informative, and engaging. Grief is sad and confusing, but your grief support doesn't have to be (Haley & Williams, 2023).



- d. **The Compassionate Friends of Canada** is an international, non-profit, peer support organization, offering friendship, understanding, grief education and HOPE for the future to all families who are grieving the death of a child at any age, from any cause. This organization offers video conferences, in-person meetings, and support groups for parents.

<http://www.tcfcanada.net>

References

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