

# Development of a Digital Information Platform to Enhance Usability and Accessibility for Immigrant Women Who Have Experienced a Miscarriage

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# Development of a Digital Information Platform to Enhance Usability and Accessibility for Immigrant Women Who Have Experienced a Miscarriage

By

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And once the storm is over you won't remember how you made it through. How you managed to survive. You won't even be sure, in fact, whether the storm is really over. But one thing is certain. When you come out of the storm you won't be the same person who walked in. That's what the storm is about.

*Haruki*

*Murakami*

## Abstract

Miscarriage is the most common pregnancy complication affecting one in four pregnancies. The loss of a baby can seriously impact women's physical and mental health, leading to traumatic disorders such as anxiety, depression, anger, self-blame, and self-harm. Women who receive support after their miscarriage are more likely to manage their mental health well. Despite this, research shows many women do not have access to the support they need after a miscarriage. Immigrant women have more difficulties accessing support due to communication barriers, cultural barriers, differences in their religion compared to their host country, and living far from family and support networks. The objective of this thesis project is to investigate the areas where immigrant women lack support and determine how the design of a digital platform can provide this support helping to improve women's well-being after a miscarriage.

Semi-structured interviews were conducted with experts in the fields of obstetrics/gynecology, psychology, grief counselling, and user experience design to better understand 1) The challenges women experience after having a miscarriage, 2) How immigrants' experience with miscarriage is different from the Canadian experience, and 3) How the design of an application could help women better manage their health physically and mentally after having a miscarriage. In addition, a co-design session with experts was held to find the design solutions and

recommendations for creating a digital platform. Lastly, the data analysis from the interviews, analysis of existing miscarriage applications, co-design session with experts and literature review were employed to develop a mobile application called *Miscarriage Corner*. The application aims to support immigrant women through their healing journey after a miscarriage. This thesis project explores the potential benefits of employing technology to improve the accessibility and usability of a mobile application to provide a support system for immigrant women who have had a miscarriage.

***Keywords:***

*Immigrants*

*mHealth*

*Miscarriage*

*User Experience Design*

## Preface

This thesis is an original work by Mehrnoush Zeidabadi. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Development of a digital information platform to enhance usability and accessibility for immigrant women who have experienced a miscarriage.”, No. 00109089, March 16,2021.

## Acronyms

**AI:** Artificial Intelligence

**APA:** American Psychiatric Association

**App:** Application

**AWS:** Active White Space

**CBT:** Cognitive Behavioral Therapy

**CUMH:** Cork University Maternity Hospital

**EPAUs:** Early Pregnancy Assessment Units

**GOe:** Global Observatory for eHealth

**HCD:** Human-Centred Design

**ISO:** International Standards Organization

**mHealth:** Mobile Health

**MIND:** mHealth Index and Navigation Database

**NHS:** National Health Service

**NIMH:** National Institute of Mental Health

**OCD:** Obsessive-Compulsive Disorder

**PALS:** Pregnancy After Loss Support

**PTSD:** Post Traumatic Stress Disorder

**PWS:** Passive White Space

**SEQ:** Single Ease Questionnaire

**SUS:** System Usability Scale

**UCD:** User-Centred Design

**UI:** User Interface Design

**UX:** User Experience Design

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## Introduction

### 1.1 Background

Miscarriage, also known as spontaneous abortion, happens when a pregnancy ends before 20 weeks gestation. Miscarriage is considered the most common pregnancy complication (Dugas & Slane, 2019), which affects between 15% and 20% of all known pregnancies. 80% of miscarriages happen in the first trimester, and the risk of miscarriage decreases after 12 weeks gestation (Dugas & Slane, 2019).

Miscarriage is a shocking and traumatic event for many parents (Gao et al., 2020). Despite miscarriage being an unpredictable event, women may blame themselves by attributing the miscarriage to their lifestyle, habits and routines. They may punish themselves and view the miscarriage as a personal failure that can affect their self-esteem and mental health. Up to 5% of women who have miscarried experience post-traumatic stress symptoms. The loss of the baby can trigger anxiety, depression, anger, and an urge to self-harm. It may take years of deep grief after a miscarriage for women to recover (Alqassim et al., 2022). The care women receive after a miscarriage plays an important role in their emotional recovery (Hiefner, 2020).

Several studies show that most women do not receive enough care from partners, family/friends and healthcare professionals; the three main groups women rely on for care after a miscarriage (Hiefner, 2020; Layne, 1997; Petts, 2018; Rowland and Lee, 2010). Since miscarriage often occurs in the first trimester before revealing pregnancy family and friends generally do not know if a miscarriage happens (Petts, 2018). If family and friends know about a miscarriage, they still may do not know how to react and help. People may act as nothing happened or try to minimize the importance of the experience (Hiefner, 2020; Layne, 1997). Lack of support from partner, family and friends contribute to psychological morbidity following a miscarriage or other traumatic events (Lee & Slade, 1996). Findings also shows women receive inadequate care during

## *Chapter 1: Introduction*

and after a miscarriage from healthcare professionals (Rowlands & Lee, 2010) leading miscarrying women to experience unpleasant emotions (Baird et al., 2018). Lack of empathy, not being considered as patients, use of medical words to address their pregnancy or loss and lack of clarity with the physical procedure are some issues women experience in their interactions with the healthcare system (Baird et al., 2018; Layne, 1997).

A large number of Canadian populations are immigrants (22%) (Turin et al., 2020). In this study, the term “immigrant” refers to any person who is born outside Canada and has immigrated to this country. Compared to Canadian-born people immigrants, especially newcomers, are more likely to experience difficulty accessing healthcare. These difficulties include but are not limited to language barriers, cultural differences, lack of information about accessing or navigating services, discrimination, insufficient social support, and expectation differences (Kalich et al., 2016; Woodgate et al., 2017). These barriers have great impact on women’s experience of a miscarriage. It is essential to make sure the provided support for women after a miscarriage is accessible for this population.

The expansion of mobile technology, particularly mHealth apps, has created novel opportunities to provide the world’s population with health-related information (Zawati & Lang, 2019). mHealth applications have the ability to support people physically and emotionally by providing quick and easy access, transfer and tracking of health information with interactive displays and visual interventions which are more engaging for users. These interventions can help promote better health outcomes by changing health-related behaviours (Han & Lee, 2018). mHealth mental health applications offer an opportunity to expand the availability of quality mental healthcare through cost-effective and scalable solutions according to public health organizations like the UK’s National Health Service (NHS) and the U.S. National Institute of Mental Health (NIMH). Mobile applications are a good choice of

psychological treatment delivery compared to other platforms due to (I) ease of habit, (II) low effort expectancy, and (III) high hedonic motivation (Chandrashekar, 2018, p. 1).

## 1.2 Objectives

The study has three main objectives:

1. Understanding the current process in which women receive physical and emotional support after a miscarriage.
2. Identifying the areas that lack support for women experiencing a miscarriage.
3. Designing a digital health solution/digital information platform to provide further support for women who experience a miscarriage.

## 1.3 Research Method and Analysis

The following research methods were employed to achieve these goals:

### a. Semi-structured Interviews with Experts

Semi-structured interviews help to have a more in-depth discussion with the interviewee and gain insight into their thoughts and feelings (Dejonckheere & Vaughn, 2019). Semi-structured interviews were conducted online, through Zoom, with two groups:

**Obstetricians/gynecologists, psychologists and grief counsellors (n=7):** For the first group, experts in the field of obstetrics/gynecology, psychology and grief counselling were interviewed. These three groups were chosen since they are the main source of physical and emotional support for women who experience a miscarriage.

**User experience designers (n=2):** For the second group, two user experience designers with experience in mobile health design were interviewed.

**b. Existing Miscarriage Application Analysis**

To understand the current status of the existing applications five miscarriage applications were analyzed. Three applications focus specifically on miscarriage, one focuses on pregnancy after a miscarriage, one provides information about bleeding during the first trimester, and one is a pregnancy application with a section for miscarriage.

**c. Co-design Session with Experts**

A participatory approach was chosen to bring healthcare professionals in different fields with a vested interest in miscarriage together to design a digital solution for immigrant women. The co-design session helped me identify some of the problems that immigrant women face after a miscarriage and the ideas and solutions for solving the stated problems.

**d. User Testing**

Three immigrant women from India, the Philippines and Iran participated in the study to evaluate the usability of the designed application. A mix of quantitative and qualitative methods was employed to find areas of confusion, uncover opportunities to improve the application and learn about immigrant women's behaviour and preference.

## 1.4 Chapter Overview

My thesis project research support document has five sections:

**Introduction:** This section contains the background and problem statement, objectives of the study, and the research methods that were employed to conduct this study.

**Literature Review:** This section has the review of the existing literature on miscarriage, the areas that women lack support after a miscarriage, immigrants and healthcare, mobile health technology and existing research on supporting women after miscarriage and abortion.

**Qualitative Analysis:** This section includes the analysis of semi-structured interviews with experts in the field of obstetrics/gynecology, psychology, grief counselling and user experience design as well as analysis of existing miscarriage mobile applications. The second section of the chapter covers the user-centred design approach which involved a co-design session with experts, user personas and storyboard creation.

**Design Outcome:** This section explains the design opportunities extracted from data analysis and the design process for creating a digital health solution prototype to support immigrant women after a miscarriage. It showcases the final digital health prototype *Miscarriage Corner* and a user testing the prototype with immigrant women and iterations of the design based on their feedback.

**Conclusion:** This section outlines the research findings, limitations and future recommendations for the study.

### **1.5 Summary**

This thesis project aims to explore the ways technology could promote accessibility and usability for immigrant women after experiencing a miscarriage. It is important to better understand what women need after a miscarriage physically and emotionally, and how a mobile application could provide this support for them.

## 2. Literature Review

### 2.1 Miscarriage

Miscarriage, also known as spontaneous abortion, happens when a pregnancy ends before 20 weeks gestation. Miscarriage is considered the most common pregnancy complication (Dugas & Slane, 2019), which affects between 15% and 20% of all known pregnancies. It usually happens due to a chromosomal abnormality in the embryo or fetus (Rogers et al., 2019). 80% of miscarriages happen in the first trimester, and the risk of miscarriage decrease after 12 weeks gestation (Dugas & Slane, 2019).

Miscarriage is often a shocking and traumatic event for parents (Gao et al., 2020). Since the ease and high reliability of home pregnancy tests enable families to verify pregnancy at an early stage, parents can also develop an early attachment to the fetus. In addition, the use of ultrasonic scanning devices has made visual attachment possible (Petts, 2018) —an option that was not available for previous generations. The attachment solidifies when parents engage in activities such as planning for the pregnancy, visiting the doctor, pregnancy announcements, and preparing for the birth. News of a miscarriage can be the source of great sorrow (Klein, 2020) afflicting the personal, social, and professional lives of parents (Palas Karaca & Oskay, 2020). Scientific reports indicate the negative impact of miscarriages on the mental health of parents, causing high levels of depression and anxiety that can last up to 12 months after the incident (Johnson & Johnston, 2020).

#### 2.1.1 Causes and Risk Factors

There are certain factors that can increase the risk of a miscarriage such as genetic (e.g., embryo/parental chromosomal abnormalities), endocrine (e.g., maternal thyroid disease, diabetes, polycystic ovarian syndrome, luteal phase defect), immune (e.g., the antiphospholipid syndrome, the presence of antithyroid antibodies), infections (e.g.,

TORCH infections, bacterial vaginosis), anatomical (e.g., uterine malformations, cervical incompetence), and thrombophilia (Tranquilli, 2012). Alongside these factors, higher maternal age and previous miscarriage experiences are the most common reasons for this incident. As age increases, the risk of miscarriage also increases due to the increased incidents of trisomy pregnancies, especially for women older than 40 (approximately 50%) (Shorter et al., 2019). Miscarriage happens in 40% of pregnancies among women at 40 years of age. The rate is between 9% and 12% for 35-year-old women (Johnson & Johnston, 2020; Palas Karaca & Oskay, 2020). Despite the various reasons listed, accurately assessing the role of a single element in diagnosing the causes of miscarriage is challenging since miscarriage is a complex disorder with a wide range of causes (Tranquilli, 2012).

## **2.2 Lack of Support After Miscarriage**

### **2.2.1 Lack of Societal Recognition**

Miscarriage is an event of great loss that leads to grieving and requires extensive coping. Grieving a miscarriage can seem like grieving other losses, but coping with it can be especially difficult due to the way it is viewed in society (Petts, 2018), where miscarriage is rarely considered a significant incident. It mostly happens because miscarriage often occurs before a viable pregnancy, or because people are generally unaware of a woman's pregnancy during the early stages unless they are informed by the parents (Petts, 2018). Even in the case of close friends, people are often unaware of others' pregnancies before the 12th week, which is the socially acceptable time for pregnancy announcements (Klein, 2020). As a result, parents often grieve alone and cope with a miscarriage without viable support from others (Petts, 2018), causing an experience of loneliness and isolation (Klein, 2020).

### **2.2.2 Lack of Social Support**

Parents' emotional recovery, following a miscarriage, is heavily influenced by the support they receive. However, family and friends as the main source of support are mostly unable to help due to making statements that minimize the significance of miscarriages (Hiefner, 2020) or acting as if nothing has happened (Layne, 1997). It should be emphasized that these circumstances are not necessarily an absence of sympathy, but rather the lack of conventional social behaviour in these situations (Layne, 1997). According to both qualitative and quantitative data, women who receive social support are more likely to manage the miscarriage better (McGreal et al., 1997; Thomas & Striegel, 1995). The crucial role of people offering such support should be emphasized since research suggests that women benefit most when they receive support from parents or other women who have had previous experiences with a miscarriage (Rowlands & Lee, 2010).

### **2.2.3 Healthcare Support After Miscarriage**

In Canada, similar to many other countries, miscarriage is managed in the emergency department, and women are referred to this department if they go to the hospital with the signs of a miscarriage. Women may also receive care from professionals such as doctors, nurses, midwives, and at Early Pregnancy Assessment Units (EPAUs) (Freeman et al., 2020; Palmer et al., 2019). Therefore, after a miscarriage, the first reference for the parents is often healthcare providers who can inform, advise, and help them to cope with the loss (Heinfer, 2020).

Despite the importance of receiving care after a miscarriage, qualitative findings show women do not receive adequate medical care during and after their experience (Rowlands & Lee, 2010) leading miscarrying women to experience unpleasant emotions (Baird et al., 2018). These women report examples of medical care as involuntary placement in maternity wards, lack of sympathy while waiting for gynecologists (Rowlands & Lee, 2010), and their medical recognition as neither grieving mothers nor

patients by healthcare providers (Layne, 1997). They note that miscarriage for healthcare providers is a routine or normal occurrence that creates no compassion and 'dismissive' or minimalizing (Freeman et al., 2020). In a study by Freeman (2019) several women expressed their unfamiliarity with and uncertainty about the treatment procedure or expectation (Baird et al., 2018), and those receiving the treatment considered the visit rushed or insufficient in satisfying their informational and emotional needs (Freeman et al., 2020). A study by Séjourné, Callahan and Chabrol showed that 78% of 300 French women did not receive adequate information regarding the causes of their miscarriage, and 82% of them remained concerned about future pregnancies post-treatment (Séjourné et al., 2010). Another study showed that most of the 15 miscarrying women participants were confused about the follow-up required or what to expect—some returned to the emergency department, some did not show up for the follow-up, and some others inquired about the ways to prevent future incidents. One participant stated, "No one talked to me about why miscarriages happened or what's the likelihood of it happening again" (Baird et al., 2018). Generally, post-miscarriage treatments are primarily focused on physical symptoms rather than emotional ones (Baird et al., 2018) and women do not receive adequate information about community supports or about how they could effectively receive adequate/appropriate mental treatments (Freeman et al., 2020). Research shows that neither the language nor the attitude of healthcare providers is emotionally sensitive for women experiencing a miscarriage. The typical use of medical terms such as 'abortion' for describing loss, or 'products of conception' or 'fetus' while describing the remains of the pregnancy can lead to feelings of isolation in medical settings (Freeman et al., 2020). On the contrary, those women who receive compassionate care and are acknowledged by healthcare providers express positive points about their healthcare experiences (Freeman et al., 2020).

In addition, research shows that since miscarriage is not mentioned in most birth classes, parents suffer from a lack of pre-miscarriage education, and they are generally unaware of the high rate of miscarriage until they experience one. Most participants in a

recent survey, measuring general perceptions of miscarriage in the United States, were unaware of the occurrences and causes of miscarriages (Bardos et al., 2015), making them more anxious when the miscarriage happened. Pre-miscarriage education in outpatient settings can make women prepare to deal with the most common causes or symptoms of miscarriage (Baird et al., 2018).

### **2.3 Miscarriage and Mental Health**

The impact of miscarriage can be psychological as well as emotional (Palmer et al., 2019). Sadness, guilt and self-blame are the most common feelings women experience after a miscarriage (Freeman et al., 2020). A woman's reaction after a miscarriage can be divided into four categories: (1) a grief reaction, (2) a depressive reaction, (3) a combined depressive–grief reaction, and (4) no reaction (Beutel et al., 1995). Research findings show that the typical sorrow following a miscarriage is generally similar to normal uncomplicated grief, first marked by shock and denial and then by sadness, guilt, shame, helplessness, and hopelessness, with possible somatic symptoms such as lower abdominal pain, cramping, back pain, absent periods, and the passing of tissue or clots (Danielsson, 2021; Toffol et al., 2013). While the grief lessens over time in most cases, it can sometimes last longer than six months, resulting in a condition known as 'complex grieving,' often accompanied by a depressive reaction. Complex grief can cause psychiatric complications, including PTSD, anxiety disorders, major depressive disorder, recurrent obsessive-compulsive disorder, and suicidality (Toffol et al., 2013). Women experiencing a depressive or a grief-depressive reaction may require specific care and can go through a long-term depressive period, whereas women experiencing a simple grief reaction do not generally require any psychotherapeutic help (Toffol et al., 2013).

Miscarriages can trigger serious and chronic mental health issues in some women, for example, those with mental health conditions before the loss, those without living children, those dissatisfied with the care they receive from healthcare providers after the loss, and those traumatized by the loss (Rogers et al., 2019). compared to women

having live births, women having a miscarriage or an induced abortion appear to be at a higher risk of lifetime alcohol or substance misuse, and affective disorders (Toffol et al., 2013). In many cases, women have feelings of guilt and self-blame. They feel nutrition, exercise, prior birth control use, and carrying heavy objects could have led to a miscarriage. “There tends to be a lot of questions afterwards, like, ‘Have I been too stressed at work? Did I eat something wrong?’” they also blame their own body for the betrayal (Klein, 2020).

#### **2.4 Immigrants and Healthcare Challenges**

A large number of the Canadian population (22%) are immigrants (Turin et al., 2020). With over 240,000 new arrivals each year, Canada is a major destination for immigrants around the world (Ahmed et al., 2015). Immigrants are very diverse in personal characteristics, place and culture of origin, migration experience, length of residence, and, most importantly in the case of this study, predisposition to disease (Long, 2010). Compared to the average Canadian-born population, immigrants are generally healthier upon their arrival. This situation is called “the healthy immigrant effect” (Gushulak et al., 2010), related to the selection process for immigration, favouring healthier and educated people (Ahmed et al., 2015). However, when they try to fit into the physical, social, environmental, and cultural aspects of Canada, they lose their high health level and assimilate with the average population. This is called “the convergence paradigm of acculturation” (Setia et al., 2010). Shockingly, the rates of alcohol consumption, obesity, depression, and chronic disease rise among immigrants (Ghahari et al., 2020). A study shows that health deterioration is far higher in non-European immigrants compared to their European counterparts (Prus et al., 2010).

Accessing healthcare is crucial for having a healthy population and is defined as the capacity to navigate health services and establish effective communication with healthcare providers (Ghahari et al., 2020). Adjusting to a new country is a highly stressful experience that can turn into a difficult process if patients do not know the

new healthcare system procedures (Setia et al., 2010). Research shows that compared to Canadian-born people, new immigrants are more likely to experience up to two and a half times more difficulties accessing immediate healthcare. These difficulties include but are not limited to language barriers, cultural differences, lack of information about accessing or navigating services, discrimination, insufficient social support, and expectation differences (Kalich et al., 2016; Woodgate et al., 2017). Communication and cultural differences are two major issues when navigating the Canadian healthcare system (Ahmed et al., 2015). New immigrants' self-advocacy in navigating the Canadian healthcare system is hampered by low confidence and poor language proficiency, impeding successful communications in expressing their needs (Ghahari et al., 2020). Not wanting to be a burden on others, removal of medical procedures in one's life, inability to exercise personal beliefs as before, and adaptation to only certain aspects of the Canadian lifestyle (e.g., diet, work-leisure time) are some of the reasons for changing health behaviours in immigrants (Ahmed et al., 2015; Ghahari et al., 2020). Meanwhile, one should not neglect the Canadian healthcare system's structure which can be problematic, since it can be significantly different (in areas such as access, equity, care process, etc.) (McAlister et al., 2018) from the ones in immigrants' home country (Ahmed et al., 2015).

#### **2.4.1 Immigrant Women**

Immigrant women in Canada have less access to primary healthcare services and poorer health outcomes when compared to men. The reasons can range from socially established gender norms and sociodemographic variables to their role as primary carers for family and friends (Turin et al., 2020). Their health condition can be negatively influenced by their work and family responsibilities as well as increased isolation due to language-related barriers. These can lead to social and economic isolation which can adversely be correlated with their health conditions, particularly mental health (Vissandjee et al., 2004). Women's health-related views can be different from healthcare professionals in areas such as knowledge of medical services, feeling

uncomfortable to ask about sexual health etc. It makes women see healthcare professionals as unapproachable or ignorant of their concerns (Rezazadeh & Hoover, 2018). Due to their separation from family, friends, and original community members, the well-being of immigrant women is further harmed by the loss of social support networks and post-immigration cultural isolation (Rezazadeh & Hoover, 2018). Understanding of the barriers that immigrant women face is required to observe how the miscarriage experiences of immigrant women can differ from those of Canadian-born women.

#### **a. Cultural Barriers**

Cultural factors can shape post-miscarriage experiences significantly and in a multitude of ways (Freeman et al., 2020). A study by Kilshaw et al. indicates that the experience of suffering is less personal and more influenced by culture. Women's knowledge, attitudes, and behaviours on pregnancy and miscarriage are shaped by their cultural context. (Kilshaw et al., 2017). Women's cultural discourse and personal circumstance might influence not only their understanding of miscarriage, but also what care they expect to receive after a miscarriage. Miscarriage can be seen as a nuisance by some women, whereas others view it as a great loss that requires a specific period of time for mourning (Freeman et al., 2020).

Alternatively, some cultures punish women for a miscarriage since they believe women owe their husband offspring (especially sons), and a man can divorce his wife due to repeated miscarriages. These cultures stigmatize miscarriage, and this stigmatization reinforces the tendency to ignore and keep silent about the experiences of miscarriages (Reinharz, 1988). Alternatively, in some countries like Qatar, miscarriage is acceptable and is not seen to be traumatic enough to necessitate mourning. They believe miscarriage is God's will and happens as a test for handling hardship (Kilshaw et al., 2017).

**b. Communication Barriers**

Since many of Canadian immigrants are from Asia, the Middle East, the Caribbean, and Africa, where English is not the primary language, language barriers can be a challenge when accessing healthcare services (Gushulak et al., 2010; Pottie et al., 2008). In particular, immigrant women might be unaware of culturally appropriate health-related information in their native language. They rely on media (e.g., the Internet, TV, brochures, and books), or family, relatives, friends, their family doctor, and community groups to translate the information for them (Rezazadeh & Hoover, 2018). The efficient strategy seems to be either among themselves (family and friends) because the natural language is present, or community organizations where a bond of trust exists among people they know. However, healthcare professionals have little knowledge of such bonds. This can also present as another communication barrier between immigrant women and healthcare professionals who cannot communicate effectively with these women, but also are not familiar with the communities women rely on (Kalich et al., 2016).

**c. Religion and Spirituality**

The role of religion and spirituality is essential in increasing resilience among patients facing health problems and illnesses (Riddle, 2020). Research findings show that religion can be considered as a major coping mechanism for women experiencing a miscarriage (Kalu, 2019; Petts, 2018), and it can help some grieving women to better cope with the loss (Kalu, 2019). A systematic analysis of 32 studies investigating the impact of religious or spiritual beliefs in the ability to recover after grieving indicated that 94% of the studies identified some positive effects of such beliefs (Cowchock et al., 2009). Many women viewed pregnancy loss as a means of learning life lessons, and their faith as a source of strength; using it as a coping mechanism for miscarriages (Riddle, 2020). For some women, religion can provide a feeling of purpose and meaning in life (Cowchock et al.,

2009), help them to better cope with stressful situations, and even see miscarriages as part of a divine plan (Petts, 2018).

For Christians, religion provides a helpful context for considering the significance of their loss. Parents can imagine their lost child in heaven (often in the shape of an angel) as a way to communicate their complex sensations and beliefs that are understandable for themselves and others (Layne, 1997). In addition, loss and struggle are frequently depicted in Judeo-Christian traditions as spiritually edifying, and child loss is at the centre of the soul's Pilgrim's Progress. Child sacrifice is even a part of both traditions as two grave examples, in the Old Testament, Abraham demonstrates his devotion to God by willingly sacrificing his son, and in the New Testament, God sacrifices his only son for a greater good, believing that for the love of the world, God gave up his son to redeem people's sins (Layne, 1997). Muslims believe in the idea that events are in the hands of God. This means that when a woman miscarries, she believes that her carrying baby was not meant to live, and the incident was a part of God's Will to save and protect her from more serious harm in the future (Tranquilli, 2012).

However, it is important to note that religion can make the coping process more challenging for some. Specifically, miscarriages can be viewed as a punishment from God, resulting in feelings of abandonment or feeling irritated with one's religious group. These beliefs can increase the risk of psychological discomfort following a traumatic experience (Petts, 2018) such as a miscarriage.

## **2.5 Mobile Technology and Healthcare**

Great advances in smartphone apps, especially ones related to healthcare, have made mHealth (mobile Health) a familiar technical term (Kernebeck et al., 2020). While there is no standard definition of mHealth, it can be defined as "medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring

devices, personal digital assistants, and other wireless devices” by Global Observatory for eHealth (GOe) (Osborn et al, 2019). The expansion of mobile technology, particularly mHealth apps, has created novel opportunities to provide a broad population with health-related information. More than 75% of Canadians (the majority of whom are born between 1980 and 1995) own smartphones and almost half of these people have downloaded at least one health app. Clinicians also use these apps in their daily practices (Zavwati et al., 2019).

The focus of most mHealth applications is on a specific disease (diabetes, dementia, autism, Parkinson’s), specific groups and activities, or specific health areas (Shopov et al., 2019). mHealth apps can also benefit both patients and healthcare providers by changing communication patterns (Osborn, 2019). For example, in clinical practices mHealth apps can be used to deliver disease-related education, support clinical diagnosis and/or decision making, encourage behaviour change to enhance patient adherence and compliance with treatment, and act as a standalone digital therapeutic resource (Rowland et al., 2020). The benefits of utilizing mHealth devices not only include therapeutic practices but also include extending social connections (Lee et al., 2018).

### **2.5.1 Mobile Technology and Mental Health Issues**

Smartphone apps have extensively been used to investigate mental diseases and disorders such as depression, anxiety, PTSD, addictive disorders (alcoholism and tobacco addiction), and developmental disorders. There are currently apps available for diverse medical practices, including cognitive behavioral therapy (CBT), self-monitoring, mental illness screening, psychoeducation, and mindfulness. Research findings clearly show the benefits of these smartphone apps in clinical practices (Kajitani et al., 2020). People in need of mental health assistance seek apps that are effective, easy to use, secure, communicative, and visually appealing. The participants also expressed their desire for

tracking and making connections among a variety of symptoms and mental states alongside accurate data analysis (Thach, 2018).

In the study “Developing an artificial intelligence tool for grief recovery,” an app named *Tuki* was developed to investigate and to help people experiencing grief. Inputs from the users’ situations were analyzed using Natural Language Processing to connect them with other matched users. To obtain the best user experience, the concept was tested and developed with users in workshops utilizing paper wireframes. The findings showed that the best way to process the concept is to talk about personal grief, and people benefit most when the talk occurs between people with similar grief experiences (Thach, 2018). Based on cognitive behavioral-therapy (CBT), five mHealth apps were investigated, and the findings showed that users value their ability to monitor, reflect on, and understand their health conditions. They also valued options to deliver notifications, prompts, or emails to remind users to complete associated activities (Thach, 2018).

## **2.6 Existing Research on mHealth Applications**

There are a few miscarriage applications available on the App store or Google play. There is minimal research conducted on the design of an application for supporting women who have undergone an abortion or miscarriage. The following is a brief summary of these studies.

The Pregnancy Loss Study Group at Cork University Maternity Hospital (CUMH) developed a series of apps in 2016 to distribute professional information on pregnancy loss problems and facilitate their research during data collection and analysis. The aim of this research was to create a content management system using web and mobile based apps with dual functionality; first to work as an information source on pregnancy loss for women, and second to serve as a research tool, asking users to enter their pregnancy loss experiences and help the researchers to improve their knowledge about miscarriage.

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The research group first created a website to provide users with information about pregnancy loss and CUMH facilities. Using the PhoneGap mobile development framework, JavaScript, HTML5, and CSS, an app was developed. Since informational articles were retrieved from the database into local storage, by opening the app, users were able to access information easily. A separate toolkit was included in the program and was only accessible for registered users. Using the toolkit, the users could map and record their pregnancy loss experiences using diaries and photos. Upon submitting entries of photos, the app calculated the overall emotion (positive or negative) using a word list with associated scores. Several validated psychometric scales on mental issues (e.g., The Edinburgh Postnatal Depression Scale, Perceived Stress Scale, and Self Evaluation Scale) were embedded in the app, which could calculate and display the scores for each scale. This allowed the researchers to screen and investigate the users' emotional well-being. The collected data can be used to support future clinical evidence-based practices (Lynch et al., 2016).

In another study, Gerdts, Hudaya and Belusa (2014) conducted research to facilitate the development of a prototype mHealth smartphone application to provide information about and increase access to safe-abortion in Indonesia. With assistance from a safe-abortion hotline, the researchers conducted 15 in-depth interviews with Indonesian women aged 18 and older who had safe self-induced abortions using the drug misoprostol. Four topics of interest were covered in the interviews: 1) safe-abortion information needs, 2) questions and/or concerns regarding misoprostol, 3) individual access and usage patterns for mobile phones, as well as comfort and literacy with mobile technologies, and 4) features to look for in a safe-abortion mHealth smartphone app. The study suggested that women may be interested in a smartphone app that provides information on safe abortion. Instructions on the protocol and operation of abortion misoprostol, warnings about and photographs of impostor misoprostol, reminders to take medications, information about normal side-effects, information

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about common side-effects, and geo-coded maps for local health facilities were among the features suggested for the app's design (Gerdtts et al., 2014).

In 2019, Gill et al., developed a web-based intervention based on preferences and experiences of women who underwent an abortion. The study was designed according to the 'development-evaluation-implementation' process from the Medical Research Council Framework for Complex Medical Interventions. The study had three phases. The results of Phase I showed that women used technology to manage their clinical treatments and preferred a website, having emails and notifications that could facilitate follow-up care and treatment. The extracted information from Phase I was consolidated with the help of family planning specialists and key stakeholders. The product led to the development of a comprehensive web-based platform, MyPostCare. Phase II comprised of such options as post-procedure care, emotional well-being tool, contraception explorer, sexual health, and appointment booking. In its virtual follow-up, women also received automated email notifications, linking them to MyPostCare services. Phase III of this study is currently active and processing its usability testing (Gill et al., 2019).

### **2.7 Human-Centred Design**

Human-centred design (HCD) is a design philosophy that considers a central role for the end-user in the design process (Harte et al., 2017). It focuses on effective approaches to address the issues and provide pre-planned solutions, satisfy the needs and requirements of the user (Erguera et al., 2019). That is, through a joint effort between researchers and designers and their interactions with end-users, they offer products and services tailored to practices, requirements, and preferences of end-users (Steen, 2011). This focus on people receiving products or services makes HCD different from traditional design practices, in which the focus is on designers' creativity (Heenop et al., 2019).

Rather than imposing one's preferences, HCD can be regarded as a transparent, motivating, transmitting, and interpreting process in which all members of the design

team cooperate to produce the results (Heenop et al., 2019). The task is accomplished using a range of HCD tools, often borrowed from fields such as psychology or sociology (Giacomin, 2015). Tool selection should be done with special care to offer: 1) basic factual information concerning the research participants' abilities and limitations, 2) definitions of operational boundaries and 3) insights rather than instructions (Heenop et al., 2019).

However, tension can arise between researchers, designers, and participants over differences in their research and practice worlds; HCD tries to consolidate these worlds within well-defined limits. Another tension could arise from the differences between orientations in research and design since in HCD one should first understand the present and then design for the future (Kanstrup & Christiansen, 2005).

The International Standards Organization (ISO, 2010) presents six principles for HCD:

- The design is based upon an explicit understanding of users, tasks, and environments
- Users are involved throughout design and development
- The design is driven and refined by user-centred evaluation
- The process is iterative
- The design addresses the whole user experience, including the context in which the user finds his/herself
- The design team includes multidisciplinary skills and perspectives

(Holeman & Kane, 2019, p.488).

### **2.7.1 Co-Design**

Among the six elements of HCD (participatory, ethnography, the lead user, contextual, empathic, and co-design) (Steen, 2011), co-design can be defined as a process taking into account the different backgrounds of users, researchers, and designers to enhance the efficiency and creativity in imagining and exploring ideas, to draw and discuss

sketches, and to develop prototypes. As experts of their experiences, everyday people are active participants and co-creators in the co-design process (Steen, 2011; Visser et al., 2005). Sanders and Stappers (2008) define co-design as collective creativity as it is applied across the whole span of a design process (p.6). Co-design is recognized and used as a transversal approach leading user-centred design (UCD) that investigates different domains from user-driven projects undertaken by a company to open-innovation projects completed through collaboration between a company and the user (Rizzo, 2010).

### **2.7.2 Usability**

Despite the great potential of using mHealth apps, the use of this technology is limited, and most users stop using the mHealth apps during the first five interaction experiences. A quarter of the users use the apps just once before quitting (Vaghefi & Tulou, 2019). Research findings show that users avoid apps that do not address usability, and they generally spend less than 30 seconds learning how to use an app before choosing an alternative or stop using this type of app forever (Liew et al., 2019). As such, running a usability test before a public release is arguably a necessary practice for mHealth app developers (Zhou et al., 2019).

Several frameworks have been proposed to investigate usability. The International Organization for Standardization defines usability as the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use and indicates effectiveness, efficiency, and satisfaction as its measurable features (Liew et al., 2019, P.1). Nielsen identifies five key aspects of usability—learnability, efficiency, memorability, reduced mistake rate, and satisfaction (Nielsen, 1996), whereas Sneiderman indicates 4 major attributes for usability—time to learn, satisfaction, time taken to recover from errors, and performance speed (Optimising Usability Requirements, 2014).

For Karvonen (2000), the simplicity and beauty of an app affects user experience and interpretation which can, in turn, be influenced by such factors as cultural background, age, and the amount of user experience. The users assess mHealth apps are based on 10 main factors—interface, navigation, notification, data collection, goal management, depth of knowledge, the accuracy of data and content, completeness, actionable recommendations, and user-system fit (Vaghefi & Tulou, 2019). Some believe that app developers can improve user experience by considering design, function, and user interface, and the enormous amount of provider-generated data in the portal can be incorporated with high-yield attributes of mHealth apps to enhance portal utilization, patient engagement, and health tracking (Baldwin et al., 2017).

## **2.8 Summary**

Studies show women do not receive enough care after experiencing a miscarriage. They experience a lack of support from family, friends, partners and healthcare professionals. Immigrant women may experience more challenges due to their cultural and language barriers. Sadness, guilt and self-blame are the most common feelings after having a miscarriage. Many women also suffer from post-traumatic stress disorder (PTSD) even years after their experience. Miscarriage can also trigger serious and chronic mental health issues in women. Compared to women with a live birth experience, women having a miscarriage appear to be at higher risk of addiction to alcohol, substance misuse and addictive disorders.

Technology has the potential to provide support for patients and help them manage their health and well-being physically and emotionally. The expansion of mobile technology has created a novel opportunity to support patients with health-related information. The same applies to clinicians and healthcare providers. Technology is filling the gap in providing health for patients and making healthcare more accessible and affordable for the users.



### 3. Qualitative Analysis

Qualitative analysis allows researchers to get a deep and nuanced understanding of the context (Busetto et al., 2020; Lester et al., 2020). Qualitative work requires reflection on the part of researchers, both before and during the research process, as a way of providing context and understanding for readers (Sutton & Austin, 2015). Recently, human-centred design has become more accepted in different fields of healthcare. Designing a good product or a service in healthcare is not possible without a customer-centric approach (Stola, 2018). To adopt a customer-centric approach in the design of the application, four research methods were employed:

- Semi-structured interviews
- Analysing existing applications
- Co-design session
- User testing

Semi-structured interviews were conducted with experts in the field of gynecology, psychology, grief counselling and user experience design. The interviews were concerning the challenges women experience after having a miscarriage, how immigrants' experience with miscarriage is different from the Canadian experience, how the design of an app can help women manage their health physically and mentally after having a miscarriage.

In addition to the interviews, I analyzed six existing miscarriage mobile applications based on the analysis of the interviews and the MIND framework. The MIND framework was designed for evaluating health-related applications endorsed by the American Psychiatric Association (APA). The framework has six categories: App Origin and Functionality, Inputs and Outputs, Privacy and Security, Clinical Foundation,

Features and Engagement, Interoperability and Data Sharing. The framework evaluates the applications based on the needs and preferences of patients (Lagan et al., 2021). In this chapter, I summarized my findings of expert interviews and data analysis of miscarriage applications.

### **3.1 Semi-Structured Interviews**

Semi-structured interviews are the most common data source in health-related studies and are generally used in quantitative analysis. This method allows researchers to collect open-ended data and understand the feelings, beliefs and thoughts of the participants on a specific topic (Dejonckheere & Vaughn, 2019).

I conducted semi-structured interviews with nine participants. The participants included obstetricians/gynecologists, grief counsellors, psychologists and user experience designers. All interviewees were recruited through email. Recruiting obstetricians/gynecologists was done by sending emails to the Vitala Global Health organization. Vitala is an organization that works with and advocates for women's health issues. For recruiting grief counsellors, I sent emails to a couple of miscarriage grief support programs. Recruiting psychologists and user experience designers was done by sending emails to experts in these fields. Eight interviews were conducted online through Zoom and one was conducted by email. The online zoom interviews took 45-60 minutes each. The interviews were audio-recorded and relevant portions were transcribed. For one of the interviews that was done by email, the interviewee received the questions as a PDF and provided their answers on the PDF and emailed it back. Conducting the interview in this format was the interviewee's preference.

The interview analysis is divided into two sections:

- 1) Interviews with medical experts. This includes obstetricians/gynecologists, psychologists and grief counsellors
- 2) Interviews with user experience designers working in healthcare.

**Obstetricians/gynecologists, psychologists and grief counsellors (n=7):** Dr.

Roopan Gill, Dr. Genevieve Tam and Dr. Erin Bader practice as obstetricians/gynecologists and work with immigrant women who have miscarried. Kristine Aanderson, a registered psychologist, specializes in perinatal mental health. She is the first psychologist in Western Canada certified by Postpartum Support International that supports women with perinatal mood concerns. Lastly, Patti Walker, Cyndi Mcleod and Lori-Ann Huot are the founders of three miscarriage support groups in Edmonton and Abbotsford that provide support for women who have had a miscarriage, ectopic pregnancy, or stillbirth. The experts were asked a series of questions about the care women receive after a miscarriage and how it could be improved.

**User experience designers (n=2):** Ammneh Azeim and Diana Campbell are user

experience designers with experience designing digital health solutions. Azeim is the director of user experience at Alberta Health Services and Diana is a user experience engineer and storyteller at Alberta Blue Cross. The user experience experts were asked about their design insights related to usability accessibility for health-related interactive media, their design research, challenges they face while working with healthcare professionals, and how to validate or test their design work.

The following steps were taken to analyze the interviews:

- Transcription: listen to the recording and then write down the speech word for word
- Read and review: read the transcriptions iteratively to understand the concept
- Extract the key data points: connect and identify themes within the data

### 3.1.1 Interview Analysis

The following key points have been identified and categorized into two sections:

#### **A.1 Interviews with experts (obstetricians/gynecologists, psychologists, grief consultants)/ Issues**

##### **a. Lack of Physical and Emotional Care After a Miscarriage**

It's not patient-centred or woman-centred when it comes to managing anything that's not acute. Anything that's not life-threatening. [ It's,] I feel like patients are left in the dark to kind of struggle and manage for themselves.—Tam

Most interviewees stated that women do not receive the care they need after having a miscarriage. Healthcare providers, family/friends, pregnancy loss clinics, community support, and psychologists are the most important resources women seek after a miscarriage. Healthcare providers play an important role in how the experience of their miscarriage is shaped since women have their first interactions with them. Dr. Gill, obstetrician and gynecologist, mentioned the language healthcare providers use is always very practical, which has a long-lasting negative impact on women. Cyndi McLeod, Adult Grief & Loss Services Manager at Abbotsford Hospice Society believes

that using robotic and clinical language, treating women in a rush and not providing enough information about what they need to expect after a miscarriage is counter to patient-centred care.

Lack of access to resources within healthcare was also stated by interviewees as one of the factors that can add stress and trauma to the experience. Patti Walker, founder of the ParentCare Society of Edmonton talks about the difficulty to find a physician and the additional challenge to find one that speaks the patient's language if English is not their first language.

Tam, obstetrician/gynecologist, and director of projects at Vitala Global Foundation mentioned the stress and trauma women may experience having to go through ultrasound in a different department, finding the availability of the ultrasound and waiting for the doctor to get their results (which always tends to take time). Therefore, if a woman is six weeks pregnant, from the time she starts spotting till the time they know if they had a miscarriage or not, they are left in the dark.

Kristine Aanderson, a registered psychologist and prenatal mental health certified professional, also believes women need more support than what they commonly receive at the hospitals:

At the hospital, they're like [here] we're here for you and we do all this stuff and then they just kind of send you home and say, you know, here's [here's] some lost people if you want to call them and they'll talk to you [you know] for half an hour an hour on the phone, but [there's] there's a lot more moms need.

In addition to healthcare providers, family and friends are considered one of the primary support women seek after a miscarriage. Walker said family and

friends sometimes do not provide the support women generally expect from them. They sometimes expect women to just move on and go to another pregnancy and do not give them the opportunity to grieve. Women may hesitate to share their feeling with their family and friends because they do not want to upset them. She added that immigrant women tend to have less family support since they might be alone in Canada or their family may live in different cities.

Early pregnancy loss clinics are additional resources women can seek support from after having a miscarriage. Gill mentioned the clinics are taking women out of emergency rooms, where they were historically treated, which is a great improvement. However, they still do not provide ongoing support after a miscarriage or prepare women for subsequent pregnancies. Aanderson mentioned that these clinics follow women for only two or three weeks after a miscarriage. Additionally, they cannot refer women to a psychologist because there are no public psychologists available and they are not permitted to recommend a private psychologist.

Therapy is an essential resource that helps patients to deal with their mental wellness and trauma after a miscarriage. Despite its importance, it is not easy for women to have access to therapy. Aanderson notes:

I need to know who to go to, I need the time and the resources to go to them. And I need to feel not stigmatized when I go. It's a pretty big hill to climb.

Unfortunately, the cost of therapy in Canada is high and it is not covered by most people's insurance plans. Aanderson mentioned that if people do not have a good insurance plan, they probably cannot afford therapy. Since

immigrant women tend to have lower incomes compared to Canadian-born women, the chance of having therapy is very low (Earnings differences between immigrants and the Canadian-born - The role of literacy skills Education Matters: Insights on Education, Learning and Training in Canada, n.d.)

In addition, women who have children at home, need to find a person to take care of their children to be able to attend the therapy sessions. Immigrant women with less family support in Canada have a harder time finding the support they need to attend the sessions. Bader notes:

For a lot of our immigrant population, their partners don't necessarily work in Edmonton, so they're often alone here with their children, relying on the support of [of] friends and not necessarily extended family.

Difference in prenatal and regular mental health is not yet recognized by many practitioners. Aanderson mentioned that because of the similarity of prenatal mental health and mental health, most practitioners think they can treat prenatal depression if they know how to treat depression. She adds:

There's a lot of myths and misunderstandings around miscarriage grief, that [that you need to] you need to know what you're doing. Otherwise, it's really easy to stick your foot so far down your road you can't retrieve it.

Aanderson believes practitioners should make sure they do not treat prenatal mental health if they haven't received training for that. Otherwise, this can be more harmful than useful for the patient.

#### **b. Lack of Access to Reliable Information**

According to the interviewed experts, women do not receive enough information from their healthcare providers after having a miscarriage. Walker

mentioned that women generally receive most of the information they need from Google, social media, family and friends, and less from healthcare providers. This is why women often have wrong information on why miscarriage happen. She states:

There's lots of misinformation on the internet. And I think also when you're talking to family and friends, sometimes it's not always reliable information. It is stories that have been passed down, culturally and generationally, and it's not always true.

McLeod believes women aren't sure where to go to find the information they need. Based on her experience, in rural areas accessing the information is even harder. It is not easy to find a physician and without having a physician, women do not have access to basic information about pregnancy and miscarriage.

Tam also mentioned when women come to the emergency room, they are unable to retain the information they receive from the healthcare provider. She asserts:

I have to give them the bad news in a very awkward situation. And then I have to plan with them what to do next. And they're tired. They usually already waiting for 20 hours. And then I tell them [all you have to] take all this medication. [you have to] You have to know about these side effects. You have to know how the process goes. And then remember everything I'm telling you. Or I tried to write something on a piece of paper, and then I give it to them.

She also added that especially for immigrant women it can be harder since they do not completely get what the doctor or EPL nurse is saying and because they feel shy, and they generally do not ask them for further explanation.

**c. Cultural and Language Barriers**

Interviewed experts believe that cultural and language barriers affect immigrant women's experience of having a miscarriage. Gill highlights the different kinds of support women need, which vary depending on the context and culture of where they come from. It is very important to consider the different cultural practices and how women think about loss or grief from different perspectives.

Aanderson mentioned that sometimes the practitioners in Canada may not acknowledge these cultural differences and it can cause adverse feelings in women. For instance, if a woman reaches out for help and mentions that she is living with her partner and parents at home, a Caucasian practitioner may assume she has enough support available because this is the norm in their culture. But if the woman is coming from a community with 30 or 40 extended families, having three people is not enough and the person may feel she is isolated.

Tam also believes that immigrants do not feel empowered to advocate for their own health, due to their language barrier. She asserts:

Language barriers and cultural differences often made things more challenging. [And so] for example, what I mean by cultural barriers is that sometimes they don't communicate exactly what's going on or how they feel. And they always just take the doctor's word at value, and they don't question anything. So then [so then they just don't, if you even] if they don't understand the instructions, they might not tell you because they're afraid. And then they suffer at home. And then it delays their [their] management and treatment to care. So for example, if they have a complication, they're

more likely to come later, with a complication, than a non-immigrant who feels more empowered to advocate for their own health.

Gill believes that South Asians, which are the second biggest immigrant community in Canada find it very hard to talk about sexual reproductive health. They generally celebrate birth and positive things. But when it is related to having an issue like miscarriage or abortion or sexually transmitted infection, they prefer to manage it in silence and do not seek help.

Different cultures have different beliefs on when a baby has a soul. Some believe that it is during the time of conception while others may hold the view that it is during the time of their delivery. This affects the attachment the family and friends have towards the loss of the baby. Anderson said:

In through orthodox Judaism, it's not considered a baby until it takes its first breath. So, you're not entitled to the regular grieving procedures until it's taken its first breath.

Rituals may also vary depending on the cultural background of the women. Walker mentioned that in some cultures it is appropriate for the baby to be wrapped in a white blanket, because of that sense of purity. While in other cultures, it is important that they be dressed in a particular outfit. Some believe the body needs to be buried within 24 hours and rituals are required to be performed around that. It is important for anyone that is supporting women after a miscarriage to respect all these differences. However, Walker believes just because a woman comes from a specific culture, we should not assume that they want to follow their rituals. She adds:

I had a woman that was from the Islamic faith, and the Imam had come to pick up the baby to take to the mosque, that's really interesting. But she

wasn't ready to say goodbye to her baby yet. And the Imam was literally pounding on the door saying, we need to take the baby now, we need to take the baby now. But she needed to have more time with her baby. And so that was one time where I met the mom where she needed not what the Imam needed. And I asked the staff to hold off on the paperwork to make an excuse that we didn't have a signature or something because we can't release babies without the proper signatures, because that was able to buy the mom a couple more hours. [So yeah] So I mean, that's one very specific example that I can think of, of kind of going against the culture but meeting the woman where, what her needs were.

Tam talks about the lack of willingness some immigrant women have towards seeking therapy because mental health is taboo in many non-western cultures. The lack of understanding and awareness of the importance of one's mental health and well-being as a holistic part of your health requires a lot of education. The stigma around mental health is not limited to non-western community cultures. Aanderson believes there is a lot of pressure for moms to be fine all the time. She says:

There's incredible pressure on moms to be fine, and everything is good, and everything is great, and everything is happy. And if you're undergoing IVF, it's [it's] part of your journey. And if you've had a loss, don't worry, at least you can have another one [ you know] and so there's just so much pressure to be okay, that for moms to go, Okay.

Different cultures tend to find a reason for the loss differently. Aanderson believes some cultures put the blame on women. Walker also notes:

I've had some cultures that have said, Well, it's because you ate a mango [or was because you {you} know and] and this is not true. But that has been passed down from generation to generation.

**d. Gender**

Interviewees hold the view that miscarriage has never been addressed properly considering its commonness. Tam believes the reason for a lack of emotional and financial support in this regard is because there is a perception among men that miscarriage is a women's issue. She believes there would be more programs to support patients through miscarriage if it was a men's issue.

Because it's a woman issue, [and you're like, oh it's] this just happens, you have to accept it. Women have been accepting this forever. Then we just say accept it, or decrease it on the priority list. Right. And like you say, women break through it. And maybe a lot of times they forget about it, and it becomes a non-issue. But at the time, it was an issue.

McLeod also believes women's health has not been studied with the same depth that men's health. She added:

I can imagine that it would be very hurtful to have a male doctor just sort of brush off this experience. He is never going to know what this experience is, like, ever. He may know what it's like as a husband, but his body will never experience this experience.

**e. Pregnancy after a Miscarriage**

Most interviewees believe pregnancy after a miscarriage is a very important issue and women need to seek physical and mental support before starting a new pregnancy. Anderson believes that pregnancy after a miscarriage can be a nightmare if women do not get it treated first. It is highly correlated with postpartum and peripartum anxiety and depression. Tom also mentioned:

Seeking out extra support if you feel like you've gone through a traumatic experience or didn't have enough support during this miscarriage so that [you know] you can talk about it before the next pregnancy so that you don't have any carryover baggage or burden from it.

**A.2 Interviews with Experts (Obstetricians/Gynecologists, Psychologists, Grief Counsellors)/ Design Opportunities**

**a. Normalizing the Experience**

All interviewees believe the first step in helping women who have had a miscarriage is by normalizing the miscarriage experience. Gill mentioned we should highlight that miscarriage is very common and one in four pregnancies end up in a miscarriage, so it can help women feel less lonely in their journey. She encourages women to talk and share their experiences. Bader also mentioned since family and friends generally do not share their experience of a miscarriage, women who have had a miscarriage for the first time, do not know how common they are.

Gill mentioned that miscarriage is usually a genetic issue. This is nature's way of telling women that it is an abnormal pregnancy to start with. Tam also mentioned that we should raise awareness on the fact that a quarter of women

experience depression after having a miscarriage, and women are not alone in their grief. She added that we should highlight how women are not causing a miscarriage, so hopefully, they do not place blame on themselves. Miscarriage usually happens with age and this is natural. Tam asserts:

It's not what you ate. [It's not what you] it's not that you travelled. It's not that you had a massage. It's not that you had a stressful test that day. So to kind of take away the feeling of guilt. I know people still feel guilty, because they're like, oh, my eggs are not good. But [but] in a way, if you tell them this is just normal for this age group, then hopefully, they cannot feel so bad about it.

Tam also added that showing women that famous people are having the same experience, can normalize it more for women.

McLeod believes that we should normalize the experience, but at the same time make sure we are not minimalizing it. Some women express that they do not feel advocated to ask for help since they do not want to take the time and energy of a counsellor or support person for an unimportant issue. McLeod believes we should make sure that women know they are allowed to reach out for help:

A miscarriage isn't a lesser loss than losing a child who was alive. It's still a loss of dreams, hopes, wishes of a child. [Right] So I think [I think] that they need to be reassured that it's [it's] perfectly okay for them to be reaching out for help and support.

#### **b. Providing Resources**

All interviewees believe women need to be provided with resources to be able to manage their mental and physical health after a miscarriage. Anderson

believes the rate of recovery is extremely high when women are connected with good support and resources. She also believes when women are in grief, it is very hard for them to go and find resources by themselves:

And if you're in that grief, or that trauma, or that stress, the idea of okay, well, now I need to pick between these six resources and look it up and go find it. It's just [It's] overwhelming. So, people just don't do anything and just sit on the couch and cry.

Gill believes we should make sure the resources provided are based on the geographical location of where women are located. For instance, if a person is from Ontario, they should have access to resources in Ontario. Tam believes providing women with resources can empower women to learn about miscarriage and understand what they can expect. She added we should make sure women have access to reliable and holistic health resources. The resources should address all the psychological aspects of what women are going through because miscarriage is not just a physical issue, but also a psychological and social issue.

Walker mentioned that women should be provided with different support groups. For instance, online forums where women can connect and share their stories, or miscarriage colouring books and songs where women can express themselves through art which can be also a source of healing. Additionally, there are different memorial services that are conducted throughout the year that can be a way to honour their baby.

Gill also believes that women need to have access to resources about planning a pregnancy. They also need information on contraception, since not all pregnancies are wanted and women may not want to get pregnant after a

miscarriage. Bader believes, immigrant women have less information about contraception and it is crucial for us to provide these resources for them. In her experience, some immigrant women are unaware of birth control options.

I would say in general, in my experience, that more immigrant women are unaware of what options there are for birth control. And so I think having, or just the fact that you can actually even control people to get pregnant. That's something that a lot of women don't even know, necessarily. like, depending on where they come from, right? Like if they come from, you know, like the middle of nowhere in Sub Saharan Africa, like they just have very little education. So sometimes you're starting really basic.

Providing immigrant-friendly resources is another piece that should be considered. Tam mentions:

Like immigrant-friendly clinics, immigrant friendly doctors, immigrant support groups, Facebook groups, any resources that can connect them to other people that are from their same culture or would understand what they're going through. Also support groups that are like other women having miscarriages, it doesn't just have to be immigrants, but also going through the same thing.

The simplicity of the provided resources is crucial especially while designing for immigrant population. Bader mentioned that one should always consider the level of education of the patient. In her experience, some immigrant patients have language barriers that make it difficult for them to read, which affects their accessibility to the resources provided.

**c. Physical Support**

All interviewees hold the view that providing physical support for women has the potential to help them in their recovery. Gill mentioned women who experience a miscarriage have a lot of questions regarding what is normal, what is not normal and what their bodies should expect after miscarriage. Anderson believes that if women receive the information at the right time, they experience less stress. Walker also holds the view that women are more open to accepting physical support prior to emotional support:

*It's much easier to talk about the physical changes, and people are comfortable about that, than the changes that are happening in your heart.*

Tam states that women do not need a physical exam following a miscarriage. However, if they have too much cramping, continue bleeding after two months, have a lot of pain or have symptoms of pregnancy, a follow-up is needed to make sure there is no product of conception in the uterus. Tam talks about the possibility of an application to walk women through the process of miscarriage and track their progress. She notes:

*There's a lot of research that shows that you can, you can figure out if your abortion is completed on your own without needing an ultrasound. So, if we can show that with induced abortion populations, I think we can definitely do that with miscarriage populations.*

Answering a couple of questions can help women track their progress, figure out when they need to see a healthcare provider to do an ultrasound when the miscarriage is completed, and what to expect daily:

*How has the bleeding been? Was there a point where it's really heavy? Did you feel [like] you pass clots or things that looks different than clots that*

could be like the tissue? And then how is the bleeding now? Is it getting less over time? And then when did it stop? And same with the pain, tracking the progress of the pain. It should be getting less and less. And then also tracking the pregnancy symptoms. Is it beginning less than less than so at the end, if you're bleeding is much lighter and almost finished, if there's no pain, there's no fever, and you don't have and, the symptoms are decreasing symptoms can take a bit longer to disappear because the whole corpus luteum that's producing the hormones has to shrink.

Tam mentioned that the checklist for physical tracking should be completed after two weeks to be accurate. If the user says no to pain, fever and pregnancy symptoms, we can possibly guarantee that the miscarriage is complete. A record of women's health history can provide them with helpful information when they visit a healthcare provider.

Gill believes the application could provide real-time follow up and support for women. Currently, women who experience miscarriage have access to nurses in early pregnancy loss clinics, with who they can ask questions and receive support. Gill believes a section of the application can connect women with the nurses online, despite their geographical location.

#### **d. Emotional Support**

Interviewees believe women need emotional support after a miscarriage to better manage their mental health. Anderson mentioned that the grief model psychologists used previously was not appropriate.

We used to have the grief model that was [that was] get over it. And the sooner you can get over it, and we all stop talking about it, the better society will be. We now know through research that [that] traumatizes a ton of

people. So, we've moved on to the [the] one called continuing bonds. So, anything that we can do to help facilitate the [the] continuance of the existence of baby tend to be pretty helpful.

Walker believed sometimes having a continuous relationship with their passed away babies helps women to deal with their grief better. So, providing women with activities to continue their bond, can help in their healing process. Lighting a candle periodically, writing a letter on their anniversary due date or getting a tattoo, can be some ways that help women to continue their relationship with their babies. She mentions examples of activities and traditions women have followed in continuing their bond with their lost child.

We have another family that donates this lovely little support, early loss support bag, and in there, there's a certificate for butterfly. So, you can take this certificate and pick up your butterfly and have another ritual of releasing that butterfly. Now that's not going to fit for everybody. But it is a beautiful way of saying that, you know, like butterflies, the way I look at it is that butterflies, we release them, and they're gone. But like her babies, they never ever truly gone because we always see butterflies might not be the same butterfly, but symbolically it represents the fact that babies are still with us.

...in Japanese culture, having those little jujitsu statues. I don't know if you know, those are beautiful. And those are all for miscarried babies. And I have not been to Japan. But I've seen pictures of the gardens of that, and what a beautiful way of honouring. And I know that sometimes they go back and they [they] redress it, and especially on an anniversary date. So, there's a beautiful example of how that relationship continues on.

Anderson talks about anxiety, guilt and lack of self-care support being the common mental issues women have after a miscarriage. Women punish themselves by not eating and sleeping well because they blame their bodies for not holding the baby. She also added that women have different ways to grieve, and one should not tell them if they are doing it right or wrong. Women should grieve in a way that brings them the most comfort.

Aanderson also believes a mobile application can help women to follow up with their mental health in several ways. The application can collect data on a women's mental needs by tracking and providing customized information, depending on how they feel. It can also help with monitoring women's mental health and referring them to a psychologist if needed. For this reason, the app could use a quick screener by answering a couple of questions:

You can just start with how are you feeling? And then if it's sad, has it been more than two weeks or less than two weeks of every day or almost every day? Or anxious? Has it been interfering with your ability to do regular things in your life?—Aanderson

Connecting with nature can have a positive impact on women. Aanderson talked about using images and videos of nature in the application to help women with meditation and relaxation. Walker also mentioned that women believe connecting with mountains, oceans and water can be healing for them.

#### e. Peer Support

Interviewees believe having a peer-to-peer network in which women can share their experience and help each other through a hard time, will help women feel less alone and scared. Walker talked about the importance of seeing other women that are further along their healing journey, which can help them feel

more hopeful about a better future. She also believes women supporting women is cross-culturally accepted. Women who have not experienced a miscarriage can still empathize, support and provide comfort to women who have a miscarriage. McLeod also said there is true value in mutual support. If women know they are not the only person dealing with this experience, they are more likely to accept what they are going through.

Participants also believe a chat platform can help women come together and share.

We know that people like chat platforms where they can chat with other people. or [we know that] they like to hear testimonials about other people who have gone through this. For example, what do people do when they need help? They go to their friends, and then they talk about it. They [you know] ask questions that the friends might not know the answers, but they kind of give feedback, and they give solutions and they provide support. So, I think that would be really nice to have on a platform, on a digital tool would be to have some kind of forum blog, testimonials, peer-to-peer support.—  
Tam

It is also important for peer-to-peer support to represent all the cultures and communities, so women feel they are connected. Gill believes we should make sure to have someone from each community in the live support (online nurse). Walker added about the importance of a multicultural broker-type feature in the application.

However, Anderson believes mentorship is a far better medium for helping women compared to peer-to-peer support:

Things can go badly when you are with other women who have also experienced losses. Because [like if you have had] if you're on a first-time loss, and you're in a group with woman who has had six losses, then as the person with the first time lost, your brain is immediately going to go to oh my god, I might have five more miscarriages.

**f. Support for Partners and Family Members**

Interviewees noted partners should not be excluded from the miscarriage support. Gill talked about the importance of providing support to partners by offering information, so they do not feel excluded. The support should be along the lines of how partners should take care of themselves and how to support their partners.

Some partners may grieve to the same level and some do not. Anderson believes if the partner is grieving to the same severity, they should have their own circle of support, and they should not work on their grief together. But, if the partner is not heavily affected by the grief, they can be a great support for the birthing person. In this situation, partners can be trained with basic mental health first aid. She also added that the idea of cheat sheets that she uses in her therapy sessions can help partners to learn how to support their spouse:

I call them cheat sheets [or] or cheat codes from video games terminology, which is just basically going if she's crying, what do I do? Place a hand, and we work with the birthing persons to make these flowcharts we're going to. Place your hand on her back and sit down next to her. Ask her if there is anything she needs at this moment. If she says no, go and get her a cup of tea. if she says yes, you know, do that. if she says, oh, I'm if she brings up feelings or emotions, do reflective listening, and I will teach the spouse how

to do reflective listening [of like, Yeah, it sounds like] it's really hard that you're dealing with this because a lot of spouses want to fix it.

Walker also believes sometimes partners play an important role in women's decisions especially if they come from a culture where a man tells their spouse what to expect or what to do. In this situation, it is important for the partner to have some basic information. In addition to the partner, other children and extended family will go through the miscarriage as well. Sometimes family members want to help, but do not know how. So, it is important to support them by providing helpful information.

Because it's not just the woman that's going through this miscarriage, it's also her partner, possibly her extended family if she has other children, as well and what does that mean as well for them [as well].

## **B. Interviews with experts: User experience designers**

### **a. Designing for MHealth Applications**

Interviewees believe designing for health is different from non-health apps in different ways. Campbell thinks the product needs to be designed in a way that the user feels empowered and in control. The reason is that when people are dealing with health-related issues, they feel like they are not in control of many things in their lives, and designers should not add to the stress they are experiencing:

They're stressed, they're worried, they're anxious, and we need to make sure that (that) we don't add anything on top of that to make them feel stupid, or that they don't know what they're talking about, or they somehow done it to themselves.

Campbell talks about the importance of creating a positive but compassionate experience for the user by using the right language and visuals. Azeim also believes since the user can be sick, their cognitive ability might be affected, and they might process information differently. As a result, designing for a health-related application should be designed as simple as possible and match more to what people are familiar with. Using features and visual cues that are popular and understood by most people is preferred to be used over creating an entirely new feature that would require users to have to learn how to use them. For example, using a simple drop-down calendar instead of a complicated one helps the patients track dates without any need to learn how to use the new calendar. Campbell also believes in the importance of using proactive language while designing for health. She believes that most users use the application due to a life event, and putting blame on them by using biased language is not providing the support they seek. In addition, using simple language and avoiding medical jargon is very important while designing a mHealth app for the public. The information should be easily understood by everyone without needing to Google medical terms.

While designing for health, it is preferable to provide minimum features. Campbell says the features on a mobile health application should be customer-centric. The designer should focus on the needs of the user and what is going to support them. If a feature is not going to meet the needs of the user, it should not be added to the app.

*It's more about the simplification of a process and a simplification of the site rather than adding a bunch of features.*

Azeim also believes adding unnecessary features to the product, makes it overwhelming and hard to use. She explains an activity that can help the designer recognize the hierarchy of features in the app:

In a user-centered design method, you could do a divide by dollar, like so many different activities, right? So you create a list of features, and you ask your users, you only have \$3, and you can spend all the \$3 on one feature, or you can distribute it on three more. That way you will get what's the most important feature for the users, right? And it's a very important, important activity because what I see a lot of times in the field where we haven't fully driven product management out of user centered design methodology is that business keeps driving the features.

**b. Designing for Women**

Interviewees believe designing for women is different. Campbell noted that the world is often designed and built by men, and since people tend to design for themselves, women have been marginalized. She believes North America has created an idealized perspective of women and persuade women to fit into this box. The design, in terms of both visuals and content, should break this box and should not put the same pressure media puts on women today. The use of content and visuals should help women feel calm, collected, understood and empowered.

Azeim added most women are good at multi-tasking. They have the ability to manage multiple things happening around them, and they can often manage them easier than men. In addition, it is hard to get women to trust an application, especially when you are designing for educated women. Educated women need to know the source of the information to be able to trust the application. The designer should provide all the relevant details to gain their trust. Women are also community builders; they are good at creating relationships. Therefore, creating a

platform where women can share their thoughts and learn from one another is vital while designing for women.

**c. Designing for Immigrants**

Interviewees believe the language we use for immigrant populations should be simple and easy to understand, helping them make an informed decision about their health.

Language that is geared towards a grade three level to support things like new immigrants, because they obviously can't read (the) English or understand (the) English language quite the same way.—Campbell

Azeim believes we need to provide enough support to lessen the impact of a language barrier on immigrants. She says:

Ensuring that we have proper translations, right. And we write very clearly, right. And also, not too wordy. We can have like many, too many too many words and information that overwhelms them further, right. So, I think for them, like going through plain language writing over and over again, that and then making clear set of steps, right, just so that they know they can whatever they need to do and how to follow.

Campbell says immigrants may not understand the ecosystem and how healthcare in Canada works. It is vital to not assume they know this information and provide all the necessary basic information they may require about healthcare in Canada. Providing this information will help women feel more secure in what they know, and reduce the anxiety of feeling like not knowing enough.

Azeim believes immigrants are smart people who are willing to adapt and are open to new ideas. It is our responsibility to help them learn and make them feel

they are at home. Campbell talks about the importance of using culturally appropriate visuals, with colours or imagery being appropriate in different cultures. Having user testing sessions with people from different cultures can identify any biases that may exist and recognize any culturally inappropriate visuals without assuming.

#### d. Creating Personas

Both interviewees believe creating a persona can help a designer know the needs of their target audience better. A persona is an imaginary character that represents different types of users of a product, service, website, etc. (Dam & Siang, 2019). Campbell notes personas help with humanizing the experience. She also believes it is a great asset while having a co-design session with experts, instead of the actual user:

... So, you use the same perspective to get them to look inward and really imagine themselves in the other person's shoes. So, if you start this session with that, they're more likely going to look at it from that perspective than their own.

Azeim also believes personas should not only focus on the demographics of the user and where they come from but more on who they are and their needs.

### 3.2 Analysis of Existing Application Design

The analysis of the existing miscarriage applications is important for several reasons. First, it identifies what features are most important to the users. Second, it highlights what are the strengths and weaknesses of the competitors. Third, it shows me how to differentiate and improve the application I am trying to create. I evaluated existing miscarriage applications on Google Play and the App store. The criteria for choosing the applications was their relevant content. Two applications focus specifically on miscarriage, one focuses on pregnancy after a miscarriage, one provides information

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about bleeding during the first trimester, and one is a pregnancy application with a section for miscarriage. I evaluated the applications based on the framework I created from my literature review and interview analysis. I also used the MIND Framework (mHealth Index and Navigation Database) which aligns with the framework recently endorsed by the American Psychiatric Association, but includes objectives and auditable (Lagan et al., 2021). The framework can be seen in **Appendix 1**.

#### A. The Miscarriage

The miscarriage app was released in 2015 by Elizabeth Petrucelli, who has extensive experience as a birth doula, a family educator on childbirth, newborn care, and parenting. She also runs a Grieving Mystery, designed to help parents cope with pregnancy loss. The app informs the user about miscarriages and provides them with all viable options. It contains many different but related sections such as miscarriage definitions, causes of miscarriage, miscarriage options, bonding with baby, the physical and emotional experience, recovering, and pregnancy after a loss.

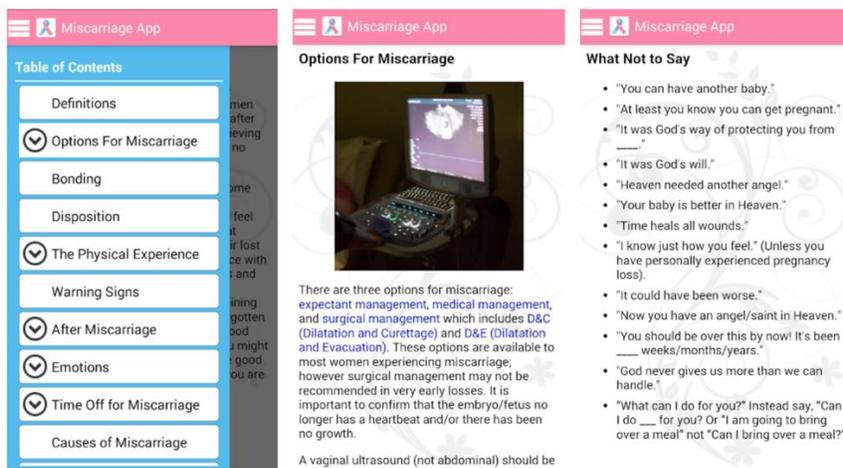


Figure 1: The Miscarriage mobile application

### B. Miscarriage Warrior

The Miscarriage Warrior app was first released by Places App Inc. in September 2020, and is available on the App Store for download, with regular updates. The app founder, Shannon Passalacqua, experienced six miscarriages and developed the app based on her own experience. The app creates a network for miscarried women to receive recovery support after the incident. Upon the first signup, the users are asked about the number of their miscarriages and the type of assistance they require; the data will be submitted to an administrator and after his/her approval, the app connects women to a community where they can discuss their experiences, feelings, and opinions with other women and healthcare professionals while working on their healing. Bi-monthly community sessions on the Zoom platform are held to further support women.

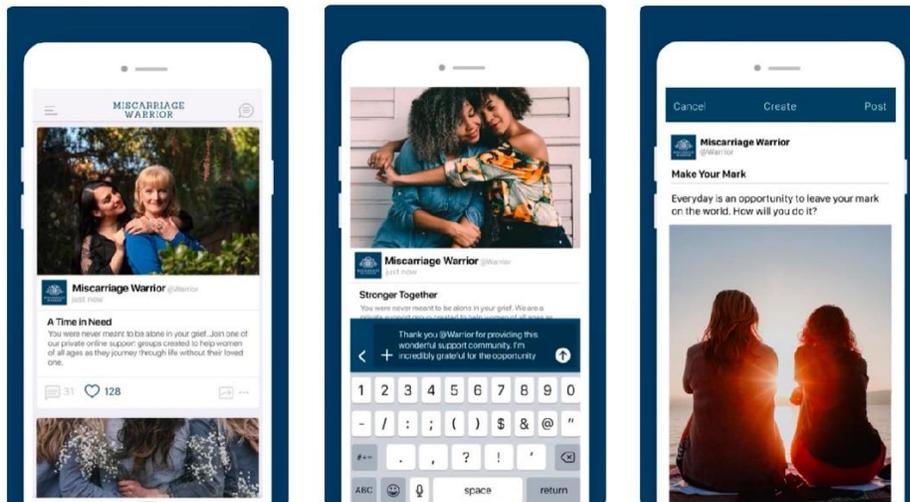


Figure 2: Miscarriage Warrior mobile application

### C. Glow Nurture

The Glow Nurture app is a customized pregnancy support app, providing users with daily updates on their pregnancy and the growth information about a fetus. The app was first

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released in July 2020 and is downloadable on Google Play and the App Store. The recent update added a section supporting postpartum and miscarriage. The users can range from a pregnant woman or a recovering one from a miscarriage, supporting both groups and eliminating the need for another app. Users have access to a diversity of miscarriage-related articles and a forum where they can talk with and listen to women with miscarriage experiences.

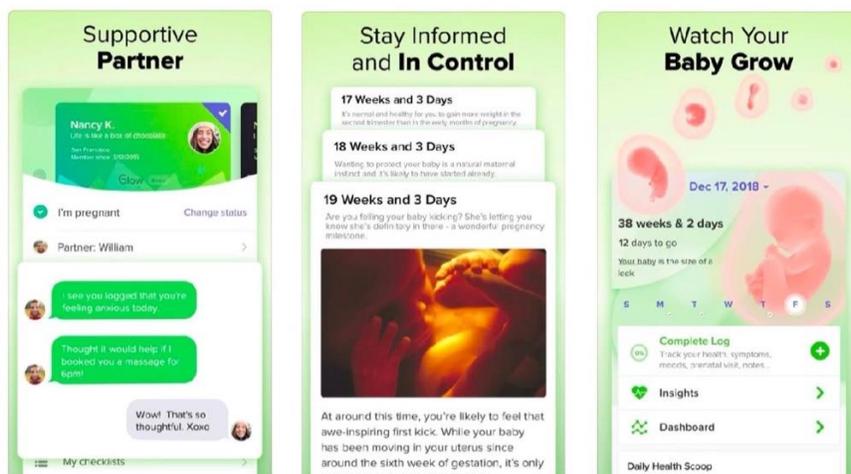


Figure 3: Glow Nurture mobile application

#### D. Pregnancy After Loss

The Pregnancy After Loss app is designed to support parents who are conceiving after a loss. The app is designed by Pregnancy After Loss Support (PALS). 50-80% of women who experience a miscarriage will conceive within 12 to 18 months of their previous pregnancy loss (Support, 2021). The app is designed to support women and their partners in the whole journey of having a baby after experiencing a miscarriage or stillborn. The app has features like customized pregnancy progress updates, coping skills and meditation, access to loss resources, link to support groups and other community members who are pregnant after having a miscarriage.

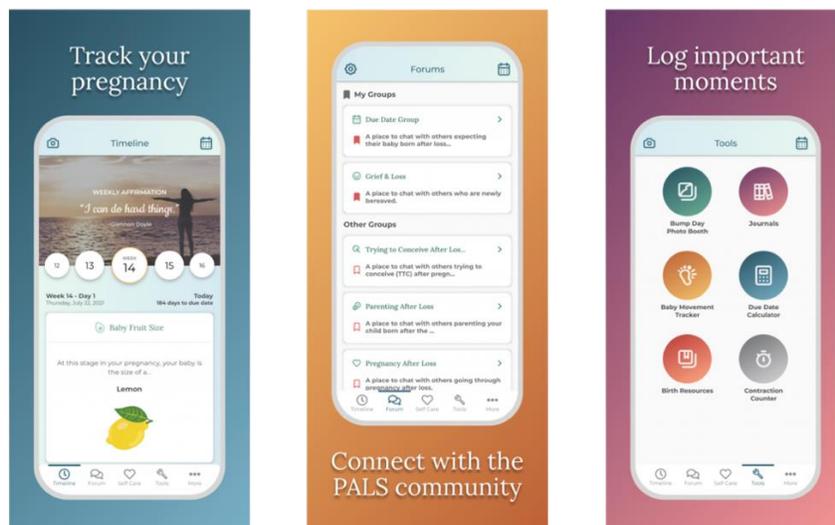


Figure 4: Pregnancy After Loss mobile application

### E. First Trimester Bleeding

The First Trimester Bleeding app is designed for healthcare professionals and clinicians based on medical literature and expert medical authorities. The app is available on Google play. The app walks clinicians through the complex evaluation of bleeding in women in their first trimester. The app answers questions such as “what information and investigations do I need for a woman with early pregnancy bleeding, how do I distinguish pregnancies which are viable, non-viable, and of uncertain viability, and when do I need serial sonograms, for early pregnancy loss, what are my treatment options”.

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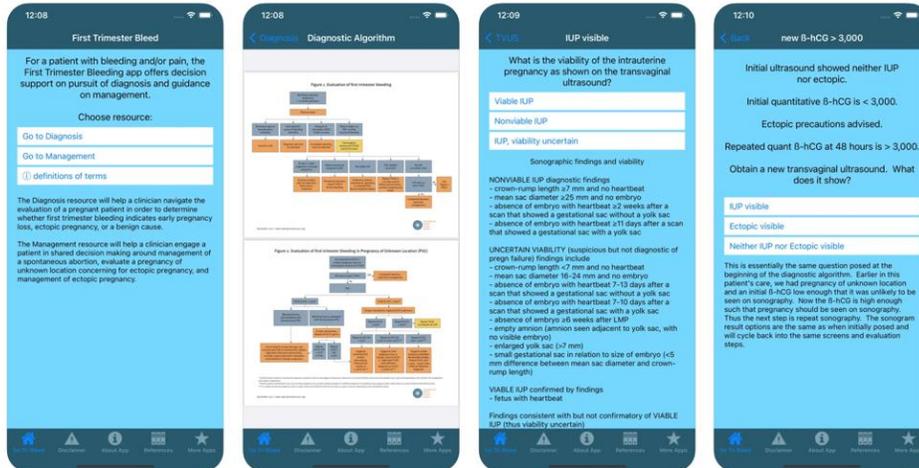


Figure 5: First Trimester Bleeding mobile application

### 3.2.1 Findings

Table 1 shows the comparison of the existing miscarriage applications. The comparison is divided into two parts: usability assessment and features.

Usability Assessment	The Miscarriage	Miscarriage Warrior	Glow Nurture	Pregnancy After Loss	First Trimester Bleeding
Size	10 MB	22 MB	69 MB	32 MB/ 42 MB	4.2 MB
Platform	Google play	App store/ Google play	App store/ Google play	App store/ Google play	App store
Offline functionality	Yes	Yes	Yes	Yes	Yes
Number of downloads	100+	500+	1,000,000+	1,000+	-
Recent updates	December 14, 2015	January 11, 2022	January 12, 2022	January 13, 2021	February 2021
Cost	Paid/ \$1.36	Free	Free	Free	Free
Language	English	English	English	English	English
Graphs or summary of user data	No	No	Yes	No	Yes

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Primary audience	Miscarried Women	Miscarried Women	Pregnant women	Miscarried Women	Clinicians
Password required	No	Yes	Yes	Yes	No
Level of learnability	Low	Low	Medium	Low	Low
Validated through research	Yes	No	Yes		Yes
Designed with medical professional	Yes	No	Yes	Yes	Yes
Use of simple language	Yes	Yes	Yes	Yes	No
Avoid medical jargon	Yes	Yes	Yes	Yes	No
Minimal design	Yes	Yes	Yes	Yes	Yes
Use of illustration	No	No	Yes	No	No
Use of nature	No	No	No	No	No

Table1: Part I: Analysis of miscarriage applications: Usability

Feature Assessment	The Miscarriage	Miscarriage Warrior	Glow Nurture	Pregnancy After Loss	First Trimester Bleeding
Connection to social media	No	Yes	Yes	No	No
Reminders	No	No	Yes	No	No
Access to history	No	Yes	Yes		No
Allow users to send data to healthcare providers	No	No	Yes	No	No
Goal sets	No	No		No	No
Step by step physical support	No	No	Yes	No	No
Physical facts	Yes	Yes	No	Yes	Yes
Step by step emotional support	No	No	No	No	No
Guided meditation	No	No	No	Yes	No

Referring to therapist	No	No	No	No	No
Access to mindfulness resources	No	Yes	No	Yes	No
Access to coping skills	No	Yes	No	Yes	NO
Access to emergency contact information	No		No	Yes	No
Live support	No	Yes	No	No	No
Mentorship support	No	Yes	No	No	No
Peer support	No	Yes	Yes	Yes	
Chat platform	No	Yes	Yes	Yes	No
Phone line support	No	No	No	No	No
Link to support groups	No	Yes	Yes	Yes	No
Support for Partner	No	No	Yes	Yes	No
Information for Family and Friends	No	No	No	No	No
Providing resources for immigrants	No	No	No	No	No

Table 2: Part II: Analysis of miscarriage applications: Features

### 3.3 User-Centred Design Approach

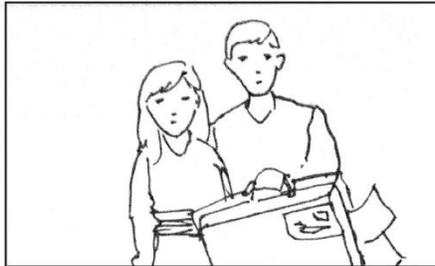
User-centred design (UCD) involves including the user throughout the design process (Abrams et al., 2004). UCD is a multidisciplinary design approach based on the active involvement of users to improve the understanding of user and task requirements, and the iteration of design and evaluation. It is widely considered the key to product usefulness and usability—an effective approach to overcoming the limitations of traditional system-centred design (Mao J. et al., 2005, P.105). In this research, a series of user-centred design approaches (including storyboards, user personas, co-design session and user testing) were used to ensure the end-user is involved in the process of designing the application.

These activities helped me better understand my users’ needs, requirements, objectives and feedback. It also let me empathize with the primary user of the application, know the ways that people will use the app and what they will do with it.

### **3.3.1 Storyboards**

I created a storyboard to help me predict and explore my user's experience visually. I employed my literature review and data analysis from the interviews to create the storyboard. A storyboard puts a human face on analytic data and lets the designer walk in the users 'shoes (Babich, 2017). Through the storyboard, I am able to better understand the background and story of my primary user and how the user interacts with the application.

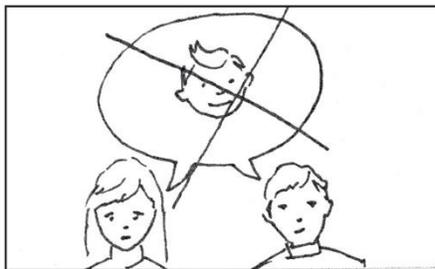
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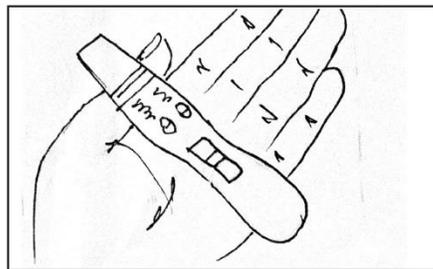
1. Fatemeh and her husband moved to Canada two years ago



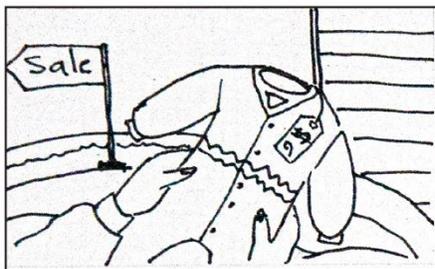
2. She starts working as a kindergarten teacher



3. Fatemeh and her husband don't want to have kids, but their families insist. In their culture, women should get pregnant at very young age



4. They consider having a baby and Fatemeh gets pregnant



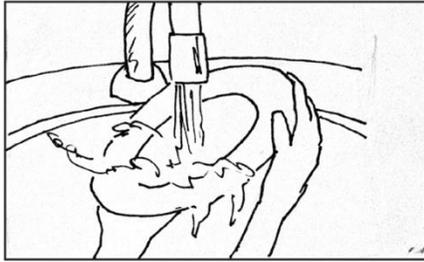
5. She starts buying clothes. Oh, it is a summer baby!



6. She plans her maternity leave

Figure 6: Storyboard I

Chapter 3: Qualitative Analysis



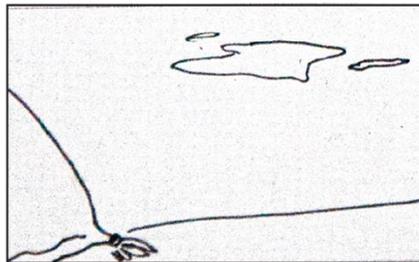
7. Fatemeh is 14 weeks pregnant  
She is washing the dishes when she realizes  
she is having cramps



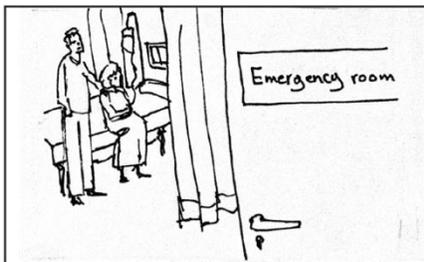
8. She immediately calls her family doctor



9. Her family doctor says it is natural to have  
cramping, but he can see her in two days



10. In the middle of the night, she starts having  
extreme pain and bleeding



11. Her husband and she go to the  
emergency room

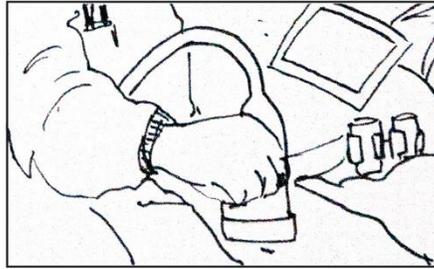


12. They are asked to wait in the waiting  
room

Figure 7: Storyboard II



13. After an hour a nurse comes and asks them to follow her



14. They do an ultrasound and it seems something is not normal



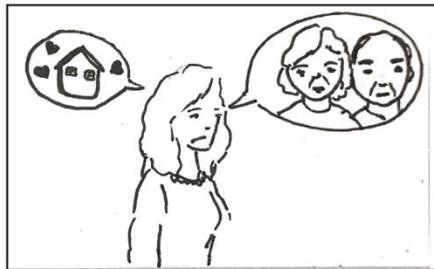
15. The doctor comes after 45 minutes and tell them the bad news



16. Fatemeh starts crying. She can't believe what happened



17. They go back home and Fatemeh tries to rest, but she is not able to sleep

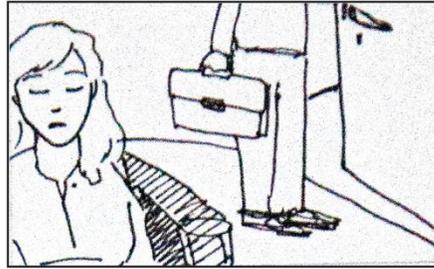


18. She can't stop thinking about what happened. She thinks it would not happen if she was in her home country and she had the support of her mother

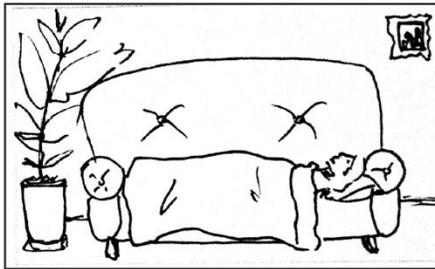
Figure 8: Storyboard III



19. Was it because I worked hard during the day? Maybe it is because of the stress I had for the possibility of my husband losing his job? What if I can't get pregnant again? How should I tell my in-law families what happened?



20. Her husband tries to be supportive, but he has to go to work



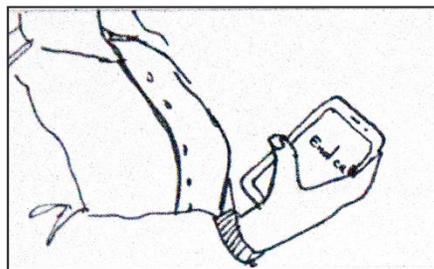
21. Fatemeh lies on the couch and cries



22. Her mother calls her



23. Her mother is weaving a sweater for her baby



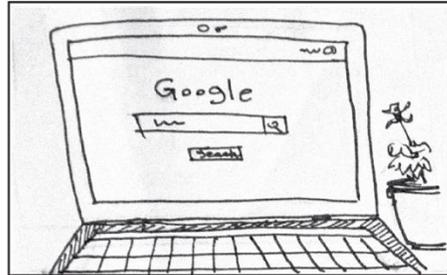
24. She starts crying and finishes the call, without telling her what happened. She is not able to share the bad news.

Figure 9: Storyboard VI

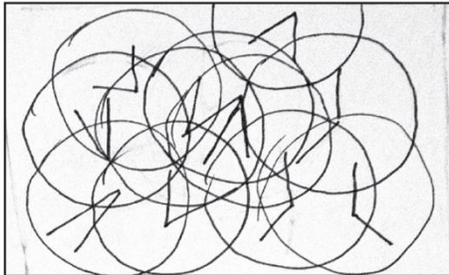
Chapter 3: Qualitative Analysis



25. Fatemeh wants to have another baby but she is not sure when they can try again



26. She starts searching but she can't find an exact answer



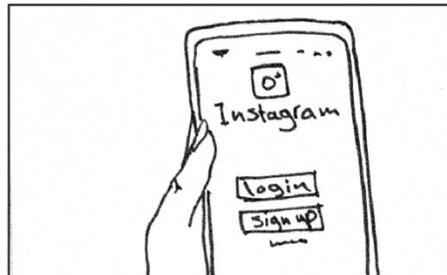
27. Time passes and Fatemeh can't get pregnant



28. Fatemeh is very lonely. She can hide things from family because they leave far, but it makes her lonelier



29. Her friends at work try to avoid talking about the miscarriage, so she doesn't get upset

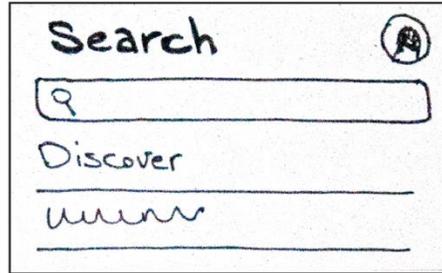


30. One day she is checking her Instagram

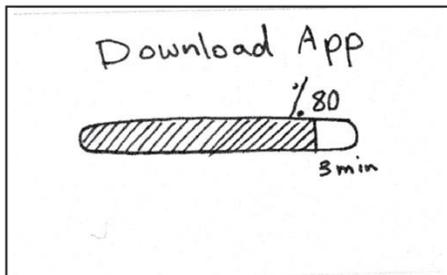
Figure 10: Storyboard V



31. An influencer talks about her miscarriage experience and how an application could help her get answers to her questions



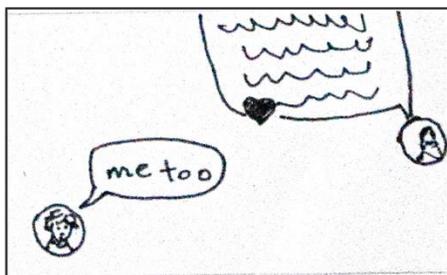
32. She starts searching on the Apple store



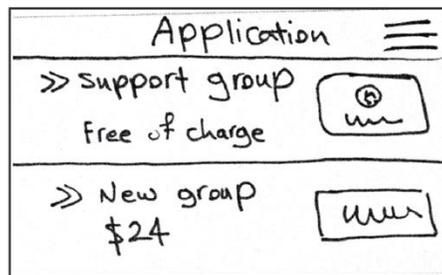
33. She downloads the application



34. She sees there is a chat platform  
She is not comfortable sharing, but she starts reading the comments



35. Other woman feels the same way as she



36. She realizes that there are support groups available

Figure 11: Storyboard VI



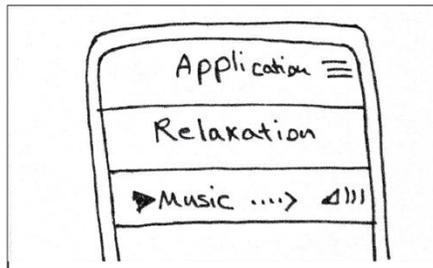
37. She attends a few sessions through Zoom



38. She is more courage to tell her family what happens. They get sad, but they try to support her



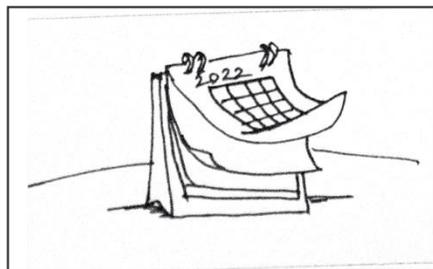
39. The next day she is in bed but she can't sleep



40. She goes to the section for relaxation that she saw earlier on the app. She plays music and tries to follow the meditation guides

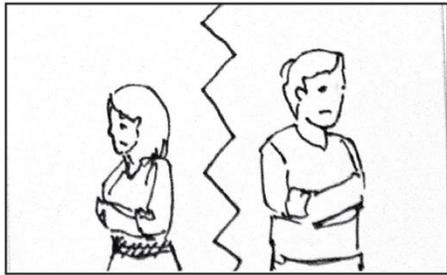


41. She feels more relaxed

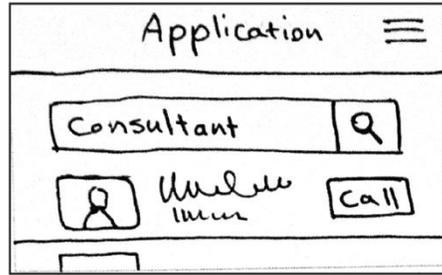


42. Time passes and Fatemeh is still not feeling emotionally well

Figure 12: Storyboard VII



43. Fatemeh and her husband start having fights about unimportant things



44. She knows she needs professional help. She goes to the app and searches for a consultant



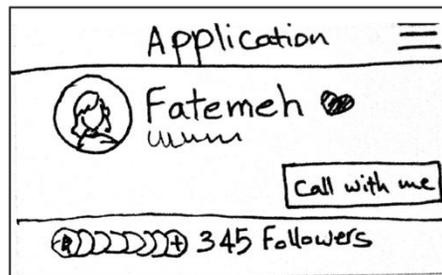
45. She calls them and books a session



46. Gradually she starts feeling more stable. Grief is still there, but it is not affecting her normal life



47. Now she is more connected to her husband and family



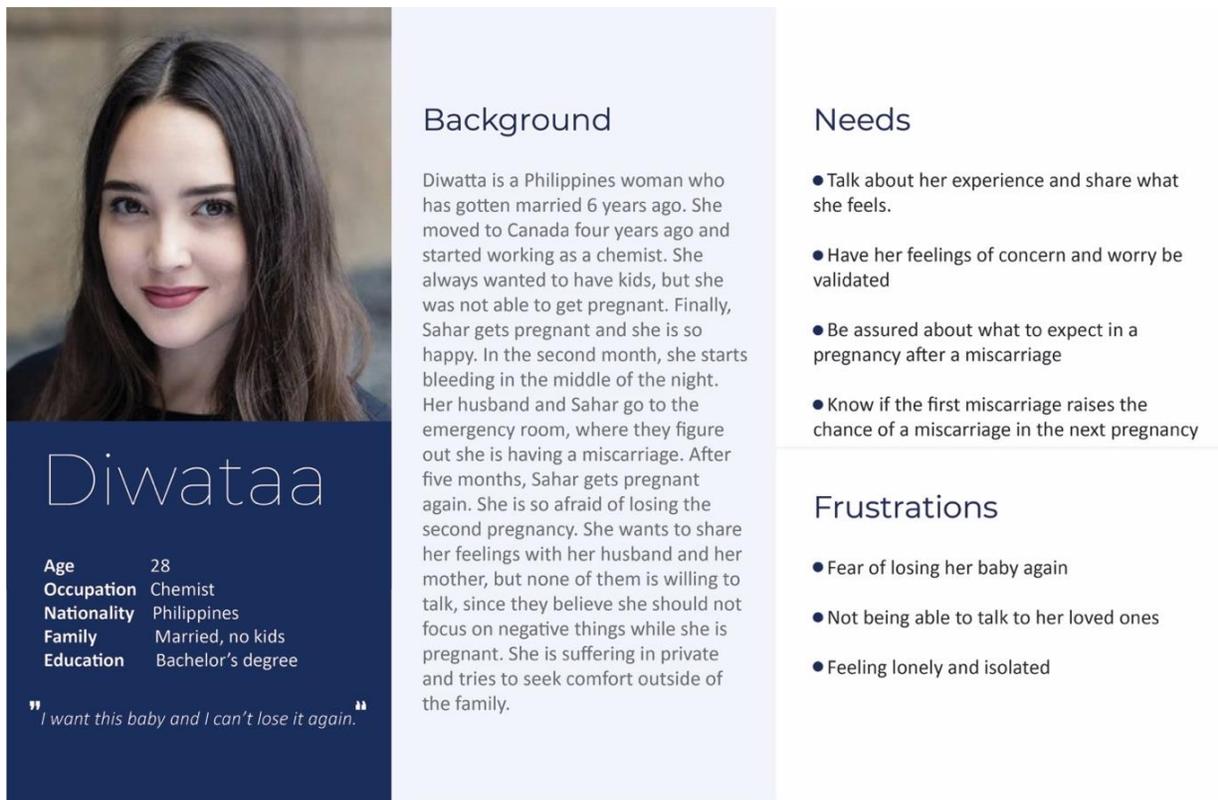
48. Fatemeh starts sharing her thought and experience on the applications. She is now a great help for others

Figure 13: Storyboard VIII

### 3.3.2 Personas

To better understand my users' needs, experiences, behaviours and goals, I developed three user personas. Based on the interviews with user experience designers, personas help stakeholders empathize with the users and look at the issue from the perspective of an immigrant woman who has experienced a miscarriage, rather than themselves. As a result, three personas were created based on the data extracted from the interviews with obstetricians/gynecologists, psychologists and grief counsellors. The personas represent different users who might use the application, their needs, goals, experiences and frustrations.

#### A. Diwata



**Background**

Diwata is a Philippines woman who has gotten married 6 years ago. She moved to Canada four years ago and started working as a chemist. She always wanted to have kids, but she was not able to get pregnant. Finally, Sahar gets pregnant and she is so happy. In the second month, she starts bleeding in the middle of the night. Her husband and Sahar go to the emergency room, where they figure out she is having a miscarriage. After five months, Sahar gets pregnant again. She is so afraid of losing the second pregnancy. She wants to share her feelings with her husband and her mother, but none of them is willing to talk, since they believe she should not focus on negative things while she is pregnant. She is suffering in private and tries to seek comfort outside of the family.

**Needs**

- Talk about her experience and share what she feels.
- Have her feelings of concern and worry be validated
- Be assured about what to expect in a pregnancy after a miscarriage
- Know if the first miscarriage raises the chance of a miscarriage in the next pregnancy

**Frustrations**

- Fear of losing her baby again
- Not being able to talk to her loved ones
- Feeling lonely and isolated

**Diwataa**

Age 28  
Occupation Chemist  
Nationality Philippines  
Family Married, no kids  
Education Bachelor's degree

"I want this baby and I can't lose it again."

Figure 14: User persona, Diwatta

## B. Priya

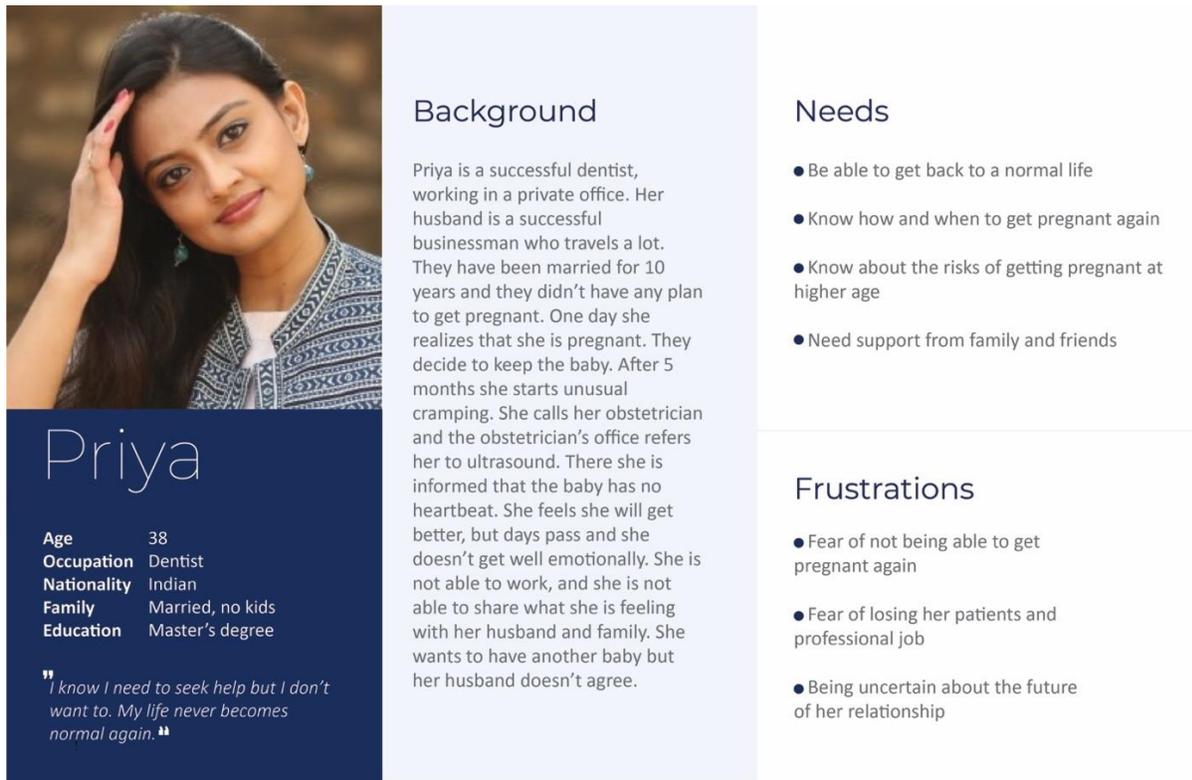
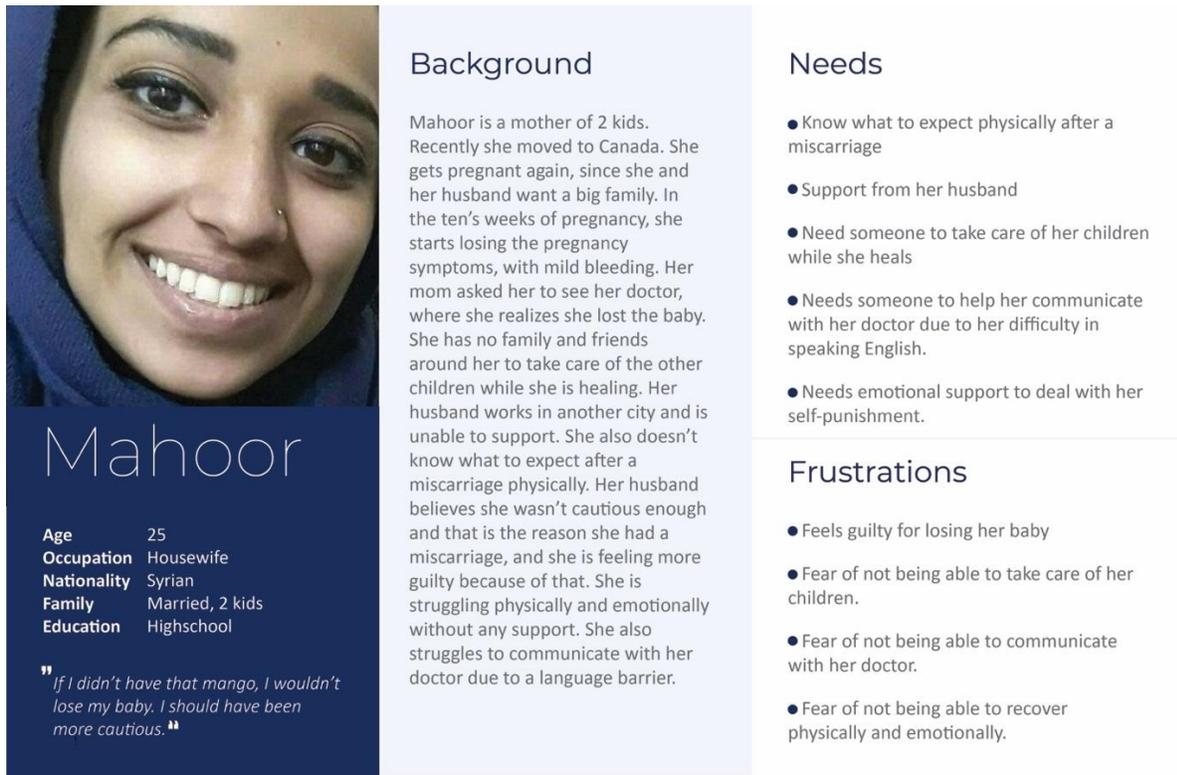


Figure 15: User persona, Priya

### C. Mahoor



**Mahoor**

Age	25
Occupation	Housewife
Nationality	Syrian
Family	Married, 2 kids
Education	Highschool

*"If I didn't have that mango, I wouldn't lose my baby. I should have been more cautious."*

#### Background

Mahoor is a mother of 2 kids. Recently she moved to Canada. She gets pregnant again, since she and her husband want a big family. In the ten's weeks of pregnancy, she starts losing the pregnancy symptoms, with mild bleeding. Her mom asked her to see her doctor, where she realizes she lost the baby. She has no family and friends around her to take care of the other children while she is healing. Her husband works in another city and is unable to support. She also doesn't know what to expect after a miscarriage physically. Her husband believes she wasn't cautious enough and that is the reason she had a miscarriage, and she is feeling more guilty because of that. She is struggling physically and emotionally without any support. She also struggles to communicate with her doctor due to a language barrier.

#### Needs

- Know what to expect physically after a miscarriage
- Support from her husband
- Need someone to take care of her children while she heals
- Needs someone to help her communicate with her doctor due to her difficulty in speaking English.
- Needs emotional support to deal with her self-punishment.

#### Frustrations

- Feels guilty for losing her baby
- Fear of not being able to take care of her children.
- Fear of not being able to communicate with her doctor.
- Fear of not being able to recover physically and emotionally.

Figure 16: User persona, Mahoor

### 3.3.3 Co-Design with Experts

A participatory approach was chosen to bring healthcare professionals and stakeholders from different fields with a vested interest in miscarriage together to create a digital health solution for immigrant women who have experienced a miscarriage. A participatory approach lets people generate the solutions and become the partners of the design process (Sanders & Stappers, 2008). Professionals were asked to use their own healthcare experience and work together to address the identified issues from the interviews. Jamboard was used as the workspace for holding the co-design sessions. Jamboard is an online whiteboard that lets stakeholders get together and engage in

ideation and brainstorming sessions in real time. It lets stakeholders express their ideas and thoughts using the software.

The co-design session took two hours with 10 minutes break. A link to the Jam board was sent to the participants 5 minutes before the meeting. At the beginning of the meeting, participants were given a quick introduction to the meeting and the agenda.

In the co-design session participants were asked to integrate in the following activities:

#### a. Preparation

**a.1 Personas:** First, personas were introduced to participants and they were asked to imagine themselves in the presented situation. This activity helped participants to think about the actual user and put themselves in their shoes. (Five minutes)

**a.2 Presentation:** Participants were presented a brief presentation on four mobile applications, two on miscarriage (Miscarriage Warrior and The Miscarriage), one on pregnancy after a miscarriage (The Pregnancy After Loss), and one on grief (Grief Refugee) chosen by the researcher. This activity was designed to help participants familiarize themselves with the concept of application design, and what has been done so far in the area of miscarriage and grief. (Five minutes)

#### b. Ideation

**a.1 Mind Mapping:** Mind mapping was designed to help the researcher identify the main problems women have after a miscarriage. In the session, participants were asked to name the most important problems they may think immigrant women have after a miscarriage, and then expand on each problem using the sticky notes. (15 minutes)

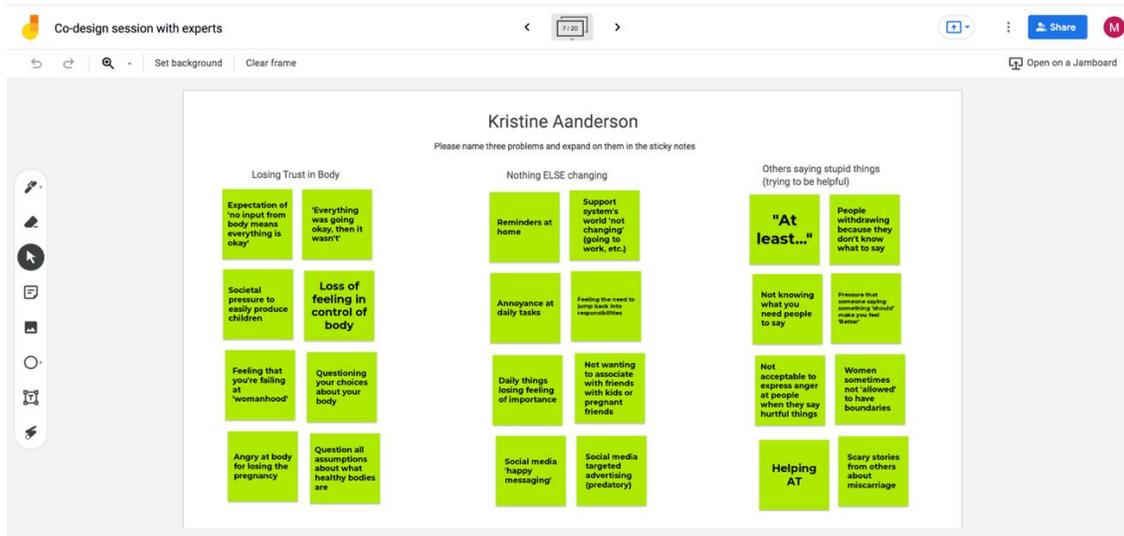


Figure 17: Screenshot of mind mapping on Jamboard

**a.2 Presenting the Idea:** Participants were asked to present the most important problem they believe immigrant women have after a miscarriage and why they think it is important. They were also asked to participate in a conversation with each other about the issue.

**a.3 Brainstorming:** Participants were led to a workspace with 10 whiteboards. Six whiteboards had titles of the design solutions that were extracted from the interviews (Normalizing the experience, providing resources, providing physical support, providing emotional support, peer support and providing support for family members). The participants were asked to add additional possible design solutions to the rest of the (plain) whiteboards that they could not find in the presented solutions. Lastly, they were asked to put sticky notes on each page and explain what would they provide for women if there were no limitations in resources. In an ideal world, what would their recommendations be on possible ways to help women through a miscarriage. It could be a button, a feature, a user scenario, a tagline, link to resources or anything they could imagine. (25 minutes)

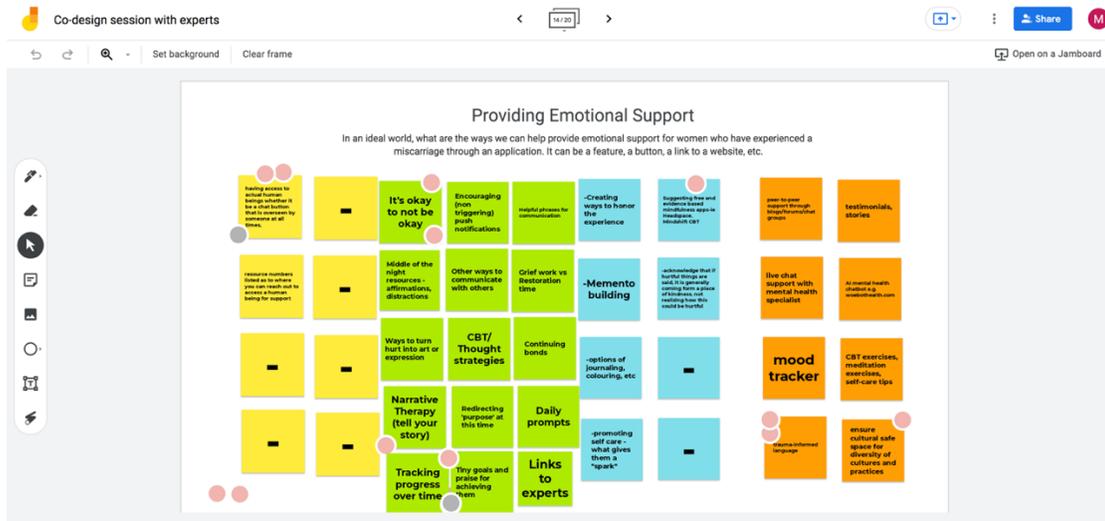


Figure 18: Screenshot of proposed whiteboards on Jamboard

**a.4 Sticky Dot Voting:** Participants were asked to go through each other's comments and ideas. In this stage, they were asked to discuss their ideas and questions that they may have about each other's sticky notes. Then they were asked to imagine they had three dollars. They could spend all three dollars on one idea or three individual dollars on three ideas, and choose the most important thing that can help women most after a miscarriage. Each participant had three dollars for each slide. Red circles were used to represent a dollar.

Participants were then asked to do the same activity but with having 100 dollars on one idea in all the slides. A grey circle was used to represent 100 dollars. This activity helps the designer realize the priority of information. (10 min)

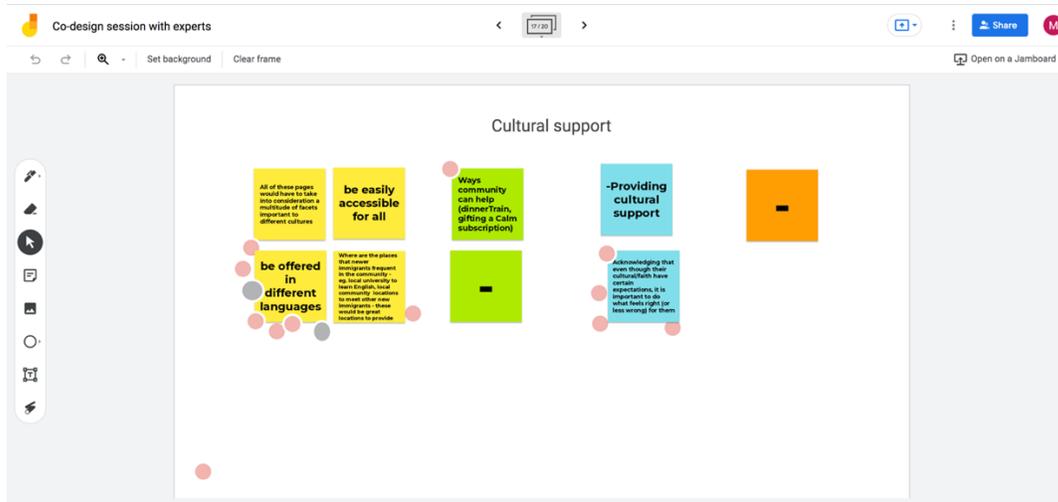


Figure 19: Screenshot of sticky dot voting on Jamboard

### 3.3.3.1 Co-Design Session Data Analysis

Issue	Collected Comments
Losing trust in body	<ul style="list-style-type: none"> <li>• Expectation of “no input from body means everything is okay”</li> <li>• Everything was going okay, then it wasn’t</li> <li>• Societal pressure to easily produce children</li> <li>• Loss of feeling in control of body</li> <li>• Feeling that you’re failing at “womanhood”</li> <li>• Questioning your choices about your body</li> <li>• Angry at body for losing the pregnancy</li> <li>• Question all assumptions about what healthy bodies are</li> <li>• Worried about age and what that might mean for a future pregnancy</li> <li>• Worried about another loss</li> </ul>
Nothing else changing	<ul style="list-style-type: none"> <li>• Reminders at home</li> <li>• Support systems “not changing” (going to work, etc.)</li> <li>• Annoyance at daily tasks</li> <li>• Feeling the need to jump back into responsibilities</li> <li>• Daily things losing feeling of importance</li> <li>• Not wanting to associate with friends with kids or pregnant friends</li> <li>• Social media “happy messaging”</li> <li>• Social media targeted advertising</li> </ul>

<p>Others saying stupid things (trying to be helpful)</p>	<ul style="list-style-type: none"> <li>• "At least..."</li> <li>• People withdrawing because they don't know what to say</li> <li>• Not knowing what you need people to say</li> <li>• Pressure that someone saying something "should" make you feel "better"</li> <li>• Not acceptable to express anger at people when they say hurtful things</li> <li>• Women sometimes not "allowed" to have boundaries</li> <li>• Scary stories from others about miscarriage</li> </ul>
<p>Lack of support</p>	<ul style="list-style-type: none"> <li>• Miscarriage is often misunderstood</li> <li>• Family and friends/society—not realizing the impact of the loss</li> <li>• Does not feel comfortable talking about emotions with husband and family</li> <li>• Unable to communicate her needs to doctor, therefore has no idea what is happening to her body physically, how to manage the symptoms, what to expect</li> <li>• Doesn't have time alone to go through and process the miscarriage, the physical side effects, and grieve. She needs to stay strong for her kids</li> <li>• No family or friends to help</li> <li>• Not sure what's available, where to get support, that it even exists</li> <li>• Husband is not supportive of her and making her feel worse</li> <li>• Feeling very alone and—not sure who to turn to for support and/or help...If a new immigrant, likely very little support from people she knows</li> </ul>
<p>Guilt</p>	<ul style="list-style-type: none"> <li>• Blames herself for the miscarriage</li> <li>• She is losing control of her body, ability to "provide" for the family, her role and purpose in the family</li> <li>• Husband blames her for the miscarriage</li> <li>• Loss of autonomy</li> <li>• Both she and her husband want a big family but she is "failing" at this objective</li> <li>• Her guilt is likely preventing her from talking about how she feels with others, even if they would be supportive</li> <li>• Feeling guilty for a whole host of possible reasons. Did I cause this? Could I have done something to prevent the miscarriage? Am I not good enough? Worthy?</li> </ul>

Lack of reliable information	<ul style="list-style-type: none"> <li>• No one to talk to about her situation</li> <li>• Unsure of wants acceptable/appropriate to share, both within her own culture, and also in this new country</li> <li>• Does not know that miscarriages are common and not caused by the women, husband also doesn't know</li> </ul>
Language barrier	<ul style="list-style-type: none"> <li>• Language barrier limiting access to support, comfort of understanding what is actually happening or has happened, where to access translation services</li> <li>• Language barrier with doctor</li> <li>• Information does not represent them due to cultural barrier</li> </ul>

Table 3: Summary of mind mapping activity with experts

Solutions	Recommendations
Normalizing the experience	<ul style="list-style-type: none"> <li>• Historical contexts for how often this happens</li> <li>• Some sort of user sticker board or something “I am here” so that people can see how many others have this (collage)</li> <li>• Trauma is a normal reaction to abnormal experiences</li> <li>• “Good moms” feel pain at miscarriage</li> <li>• Don't always have to be strong (but still be strategic for safety)</li> <li>• Normalize having happy healthy pregnancies after miscarriage</li> <li>• Reinforce the majority of times it is not within their control and not their fault</li> <li>• Acknowledge that they will continue to have a relationship with this baby (event)</li> <li>• Acknowledge how common this is—being careful with stats. The only stats that matter is 0 or 100—it happened or it did not</li> <li>• Reinforce that it is normal and understandable to be sad. It is also normal to not be sad.</li> <li>• Explain normal fertility</li> </ul>
Providing resources	<ul style="list-style-type: none"> <li>• Links to miscarriage support websites</li> <li>• Links to positive distractions (cats falling off coffee tables on YouTube)</li> <li>• Social Media links/interconnectivity</li> <li>• Connection to Early Pregnancy Support</li> <li>• List of providers</li> </ul>

	<ul style="list-style-type: none"> <li>• When to get professional help</li> <li>• Links to cultural supports</li> <li>• Algorithms to help direct to most helpful information (and a searchable library)</li> <li>• List of appropriate virtual support</li> <li>• Options for disposition (private burial, cremation, hospital burial program)</li> <li>• Print resources</li> <li>• <a href="https://pilsc.org">https://pilsc.org</a></li> <li>• Information on upcoming memorial services</li> <li>• Link to mental health resources, e.g., hotlines, chatbots, local services</li> <li>• Support groups—in person and online</li> <li>• Help guide the user through which resource she might need—"what are you looking for? information about fertility, mental health, medical side effects etc." so it is not so overwhelming to search through a big list</li> <li>• List of podcast/Ted Talk</li> <li>• Who to call in various Canadian communities</li> <li>• Keep resources current</li> <li>• Reading resources</li> </ul>
<p>Providing physical support</p>	<ul style="list-style-type: none"> <li>• 3 different levels of explanations (comforting, basic medical, advanced medical)</li> <li>• Information on what are the causes</li> <li>• Physical ways to remember their baby (tiny to bigger)</li> <li>• Pick ways to help comfort body</li> <li>• Pain management</li> <li>• Massage/self-massage techniques</li> <li>• Food or nourishment</li> <li>• "Safe" ways to reconnect with body</li> <li>• Tracker "what to expect when you're not expecting..."</li> <li>• Grounding/meditation techniques (quiet and busy)</li> <li>• Access to Healthcare Professionals who can answer questions.</li> <li>• Identify some of the physical experiences with a miscarriage</li> <li>• Discouraging the use of drugs or alcohol to numb the emotions</li> <li>• What is "normal"—when to seek professional help with bleeding, signs of infection. Include images of what bleeding looks like on a pad.</li> <li>• Clarify what blood work means</li> <li>• Miscarriage support bag (at the time of the loss—i.e., microwave warm up bags for cramps, big pads, encourage H2O) (after the loss—journal, memento)</li> </ul>

	<ul style="list-style-type: none"> <li>• Daily symptom tracker, also helpful for doctor to review if there are any concerns</li> <li>• Links to telemedicine to speak with health professionals</li> <li>• Clear description of common side effects with illustrations/images, explain what's normal, and also have danger signs of when to go to the emergency room</li> </ul>
<p>Providing emotional support</p>	<ul style="list-style-type: none"> <li>• It's okay to not be okay</li> <li>• Encouraging (non triggering) push notifications</li> <li>• Helpful phrases for communication</li> <li>• Grief work vs restoration time</li> <li>• Ways to turn hurt into art or expression</li> <li>• Continuing bonds with baby</li> <li>• Narrative Therapy (tell your story)</li> <li>• Redirecting 'purpose' at this time</li> <li>• Daily prompts</li> <li>• Tracking progress over time</li> <li>• Tiny goals and praise for achieving them</li> <li>• Creating ways to honor the experience</li> <li>• Suggesting free and evidence-based mindfulness apps-i.e., Headspace, Mindshift CBT</li> <li>• Memento building</li> <li>• Acknowledge that if hurtful things are said, it is generally coming from a place of kindness, not realizing how this could be hurtful</li> <li>• Options of journaling, colouring, etc.</li> <li>• Promoting self-care</li> <li>• Live chat support with mental health specialist</li> <li>• AI mental health chatbot e.g., woebotohealth.com</li> <li>• Mood tracker</li> <li>• CBT exercises, meditation exercises, self-care tips</li> <li>• Trauma-informed language</li> </ul>
<p>Peer support</p>	<ul style="list-style-type: none"> <li>• Support from others who have been through the exp.</li> <li>• Carefully matched supports</li> <li>• Different stories in a "suggested" bin (matched)</li> <li>• Support in their native language</li> <li>• <a href="https://pilsc.org">https://pilsc.org</a></li> <li>• Phone support, if someone needs to talk to someone that is not known to them because of shame and guilt</li> <li>• Online support groups</li> <li>• Chat platforms</li> <li>• Drop-in groups/chat</li> </ul>

	<ul style="list-style-type: none"> <li>• Testimonials from other people who have experienced pregnancy loss</li> </ul>
<p>Providing support for partner and family members</p>	<ul style="list-style-type: none"> <li>• What to say/not to say</li> <li>• To do/not do</li> <li>• Physical explanations</li> <li>• Books for kids</li> <li>• Ways to keep older kids occupied</li> <li>• Ways to reach out (text, email, letter - or culturally appropriate ways)</li> <li>• “Cheat sheets” for partners</li> <li>• Place for family members to remember/mourn/make a remembrance</li> <li>• Family member testimonials with what they found helpful</li> <li>• Suggestions for friends/extended family on how to support—bring meals, childcare, household chores (laundry, shovel snow, mow grass etc.)</li> <li>• This section could be shared by the user with her husband and family members</li> <li>• Supporting the user on how to disclose her miscarriage in safe way</li> <li>• Access to a resources page specific to family support,</li> <li>• Signs to watch for - signs may be indicative of depression or other health concerns</li> <li>• Sharing of what the person who miscarried may be feeling</li> </ul>
<p>Cultural acknowledgment</p>	<ul style="list-style-type: none"> <li>• Acknowledging that even though their cultural/faith have certain expectations, it is important to do what feels right (or less wrong) for them</li> <li>• Be offered in different languages</li> <li>• Where are the places that newer immigrants frequent in the community—e.g., local university to learn English, local community locations to meet other new immigrants. These would be great locations to provide the resources to — SARA is an organization here that could be a good alliance for this kind of information possibly</li> <li>• All of these pages would have to take into consideration a multitude of facets important to different cultures</li> </ul>

Table 4: summary of Brainstorming activity with experts

Solutions	Recommendations	Number of votes
Normalizing the experience	Support from others who have been thru the exp.	*
	It's not your fault	***
	Acknowledge how common this is—being careful with stats. The only stats that matter is 0 or 100—it happened or it did not	**
	Peer-to-peer support from others who have experienced miscarriage	**
	Acknowledge trauma/difficult experience	*
Providing resources	List of podcast/Ted Talk type of resources available to listen to,	**
	Who to call in various Canadian communities	**
	When to get professional help	**
	Links to cultural supports	*
	Algorithms to help direct to most helpful information (and a searchable library)	*
	Links to blogs/FB groups where women talk about their miscarriage	*
	Help guide the user through which resource she might need—"what are you looking for? information about fertility, mental health, medical side effects etc." so that it is not so overwhelming to search through a big list	***
Providing physical support	3 different levels of explanations (comforting, basic medical, advanced medical)	*
	Ways to help comfort body	
	Pain management	
	What is "normal"—when to seek professional help with bleeding, signs of infection. Include images of what bleeding looks like on a pad)	**
	Miscarriage support bag (at the time of the loss—i.e., microwave warm up bags for cramps, big pads, encourage H2O) (after the loss—journal, good Kleenex, memento)	***
	A clear description of common side effects with illustrations/images, explain what's normal, and also have danger signs of when to go to the ER	***
Providing emotional support	Having access to actual human beings whether it be a chat button that is overseen by someone at all times	**
	It's okay to not be okay	**
	Narrative Therapy (tell your story)	*
	Tracking progress over time	*
	Suggesting free and evidence-based mindfulness apps—i.e., Headspace, Mindshift CBT	*

	Trauma-informed language	**
	Ensure cultural safe space for diversity of cultures and practices	*
Peer support	Chat platforms	**
	Carefully matched supports	*
	Historical/cultural supports	*
	Support in their native language	***
	<a href="https://pils.org">https://pils.org</a>	*
	Phone support, if someone needs to talk to someone that is not known to them because of shame and guilt	**
Providing support for family members	To do/not do, to say/not say	**
	Sharing of what the person who miscarried may be feeling	*
	Family member testimonials with what they found helpful	**
	Section for family members on how to support someone through a miscarriage. This section could be shared by the user with her husband and family members	*****
	Supporting the user on how to disclose her miscarriage in safe way	*
Cultural Acknowledgment	Be offered in different languages	*****
	Ways community can help (dinner Train, gifting a Calm subscription)	*
	Acknowledging that even though their cultural/faith have certain expectations, it is important to do what feels right (or less wrong) for them	****

Table 5: Summary of sticky dot voting (Each \* represents one dollar)

Recommendations	Number of votes
It's not your fault	*
Links to cultural supports	*
Algorithms to help direct to most helpful information (and a searchable library)	*
What is "normal"—when to seek professional help with bleeding, signs of infection. Include images of what bleeding looks like on a pad.	*
Having access to actual human beings whether it be a chat button that is overseen by someone at all times.	*
Tracking progress over time	*

Chat platforms	*
Family member testimonials with what they found helpful	*
Be offered in different languages	**

Table 6: Summary of sticky dot voting (one hundred-dollar activity, Each \* represents one dollar)

### 3.4 Summary

Through interviews with the experts, I was able to better understand women's needs, frustrations and challenges after experiencing a miscarriage. The interviews uncovered the areas that women lacked support, as well as the opportunities that design has to create a support system for women to help them through this challenging time. Following the analysis of existing miscarriage applications and a co-design session with experts, I was able to explore different ways that technology could help to create the support women needed. The design opportunities that were extracted from these activities are discussed and built upon in the next chapter.

## 4. Design Outcome

This section explains the design process for building a mobile health application that aims to support immigrant women who have experienced a miscarriage. It starts with a discussion of design opportunities that are extracted from the literature review, interviews with experts, co-design session with experts and analysis of existing apps. The goal of this study is to better understand and present some opportunities which can be incorporated into designing a digital health solution for immigrant women who have experienced a miscarriage.

### 4.1 Design Opportunities

The following design opportunities are identified from the literature review, data analysis from interviews with experts and co-design session with experts:

#### a. Normalizing the Experience

Most women do not know how common miscarriages are. Usually, women do not hear about their family and friends' experience of a miscarriage, since people do not like to share their experience, especially when it happens before announcing a pregnancy. As a result, women can feel alone when they experience a miscarriage. They feel guilt, lose trust in their bodies and continue the cycle of not sharing their experience because of shame. Acknowledging what women are going through and raising awareness about how common miscarriage is, will help women feel more in control and less alone.

#### b. Providing Reliable Information

Women who experience a miscarriage may have questions about their physical and emotional health. Since they experience grief and trauma after a

miscarriage, it is not easy for them to search online, and verify if the information is reliable or not, Aanderson noted. Immigrant women also may find it harder to find information in their own language. In addition, women are usually busy with taking care of family or getting back to work which makes it hard for them to find the information they need and verify its credibility. Providing categorized information through an application will let women have access to authentic information on top of the hand.

#### **c. Providing Physical Support**

The first thing women deal with after a miscarriage is physical recovery. After their experience, women may have questions about what to expect after a miscarriage, when to seek help, and how to make sure if they completed the miscarriage successfully. Women are more likely to accept physical support than mental support, according to Walker. In addition, women experience less stress if they receive information on their physical health immediately after a miscarriage. Offering physical support through an application can be possible by providing answers to possible questions, links to telemedicine, pain management, and a daily symptom tracker. A symptom tracker could help women know if they need a follow-up, what to expect daily, and when a miscarriage is completed. More explanation on the features will be provided at the end of this section.

#### **d. Providing Emotional Support**

Grief, guilt, anxiety and lack of self-care are the most common feelings women have after a miscarriage. Women feel as though they cannot trust their bodies, and feel they failed at motherhood. Receiving emotional support after a miscarriage can help women to better manage their mental health. According to Aanderson, it is also crucial for women to seek mental support before the next pregnancy. An application could help women manage their mental health

in many ways. Referring to a psychologist, screening their mental health, providing resources to self-care and meditation, mood tracker, etc. are some features that can help women heal and provide self-care. More explanation on the features will be provided at the end of this section.

**e. Peer Support**

Many women are good at sharing their thoughts and feelings while providing support to one another. Creating a community of women who have experienced a miscarriage, can help women feel less lonely and isolated. According to Walker, listening to the experience of women who are a little further in their recovery will offer other women more hope in their journeys. Providing platforms such as chat rooms, phone support, one on one sessions, and drop-in groups are some of the options that can help women get support from other women experiencing a miscarriage.

**f. Support for Partners, Family and Friends**

Women are not the only partner experiencing the loss of a baby. Some partners may feel the loss very strongly and some do not. Providing a place in the mobile application for partners, will let them feel more involved and included. That section can also teach partners about basic mental health first aid, so they can help mother with their mental health recovery. In addition to partners, family members and other children may experience the loss as well. Most family members have good intentions and are willing to help, but are unable to support their loved ones, due to lack of knowledge on what to say or how to act (Layne, 1997). It was suggested by experts that providing resources such as how to offer help, what to say and what to avoid can teach families about loss and how to help mothers. Lastly, providing resources such as colouring books and story books for kids of the mothers who have experienced a miscarriage are some ways to teach them the concept of loss and grief.

**g. Cultural Support**

While designing for a diverse group of people, it is essential to make sure visuals and content are culturally sensitive. All features provided in the application, have to take into consideration a multitude of facets important to different cultures. It was suggested by user experience designers that one of the ways to do this would be to: translate the application into different languages, consider different cultural practices and ways women think about loss and grief and connect immigrants to community support groups.

Acknowledging the cultural differences of the users will make the application be more accessible and acceptable.

**4.2 Design Process**

My design process follows a Design Thinking approach. Designing Thinking is a systematic framework that prioritizes empathy for the user's needs and wants. It helps designers to deeply understand the problem the end-user is dealing with and lets them develop an inclusive and effective solution (Roberts et al., 2016). In this framework, designers start with getting engaged with people who are most affected by the problem and have the highest level of knowledge about the issue.

**a. Discover**

The first stage of Design Thinking process is to discover the insights of the user. This is possible through unbiased and open exploration of users' needs. This goal can be achieved by creating empathy with the users by understanding their context, experience and behaviour. Through interviews and co-design sessions with experts (in the three main fields with the highest interactions with women who have experienced a miscarriage (obstetricians/gynecologists, psychologists, and grief counsellors)), I was able to better understand women's needs, their frustrations, and expectations after experiencing a miscarriage.

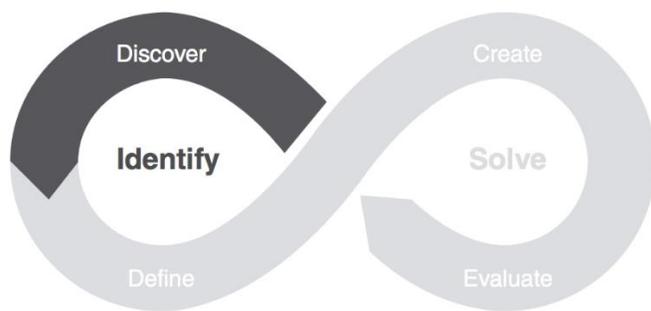


Figure 20: Discover mode (Luchs, 2015)

#### f. Define

The focus of this stage is to identify and define a problem to solve. This stage helped me focus on the most crucial need and the problem I would need to solve. Based on data analysis of my interviews and co-design session, I defined the following problem statement:

A digital platform is needed to support women after experiencing a miscarriage with their physical and emotional health. The platform could fill a gap in the lack of care women receive from partners, family/friends and healthcare professionals.

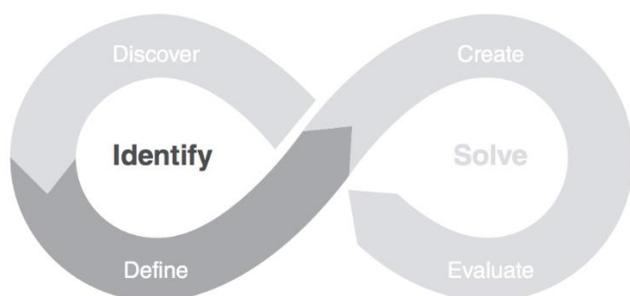


Figure 21: Define mode (Luchs, 2015)

**a. Create**

The purpose of this stage is to create a set of design concepts that can be shared with the target audience for feedback, and then to make further iterations to improve upon. The target audience are the group of people who are the end-user of a service or product. In this research, the target audience is immigrant women who have experienced a miscarriage. Based on the identified problem and the data analysis from my co-design session, I generated a series of ideas. To stay focused on women’s needs, I filtered the ideas by simplifying them from broad themes to design opportunities. Finally, I created a set of wireframes that showcased the layout and structure of my application, and I further developed them into high-fidelity prototypes of a mobile application.

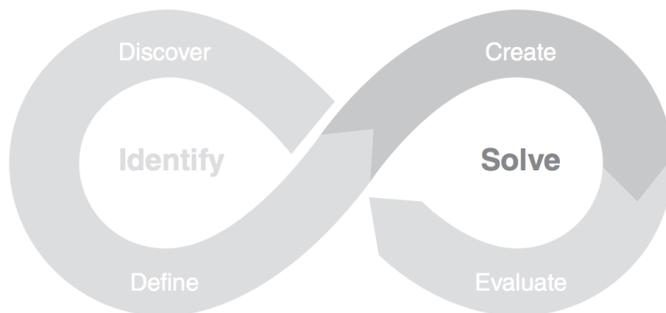


Figure 22: Create mode (Luchs, 2015)

**b. Evaluate**

Evaluate is the final mode in design thinking. The aim of this stage is to receive feedback on the prototype and refine the design. I used this stage to share the *Miscarriage Corner* prototype with immigrant women who have experienced a miscarriage and receive feedback from them on a user testing session. In this stage, a high-fidelity prototype of the application was shared with women and

they were asked to finish some tasks while thinking and talking aloud. This activity helped me realize what are the strengths and weaknesses of the application, observe real user interactions with the app, and learn how I can improve the user's experience.

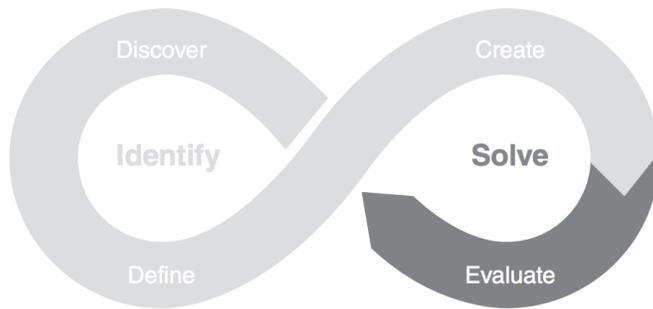


Figure 23: Evaluate mode (Luchs, 2015)

### 4.3 Design Decisions

This section explains the design decisions that were taken to create a prototype for a mobile application to support immigrant women through their miscarriage. A prototype is a valuable tool that helps with exploring different design solutions and constantly refining them. With the increasing adoption of design thinking in the product development process, early-stage prototyping has become an important tool (Elverum et al., 2016). In this study, I used prototyping to first build the mobile application based on experts' recommendations and literature review, and second, evaluate the design with immigrant women.

#### 4.3.1 Logo Design

Logo design is the fundamental component of the visual identity and helps the product stand out allowing users to connect with the application and remember it (Carson & Airey, 2022). *Miscarriage corner* (**Figure 24**) is a mobile application that helps immigrant women manage their physical and emotional health after a miscarriage. Since

immigrants are the main users of the application, the name should be easily identifiable with miscarriage. Adding “miscarriage” as part of the name makes it easier to find on the App Store or Google Play. The purpose is to make the communication very obvious and direct, to avoid miscommunication. Miriam Webster’s definition of “corner” is a private, secret, or remote place. Including “corner” in the title helps show the importance of privacy and secrecy which is crucial for the application. *Miscarriage Corner* illustrates a safe space for women to share their experience, receive support and learn about miscarriage. The main elements of the logo design are a heart, a woman’s belly and a women’s hands. Active white spacing (AWS) was used as the method to illustrate the missed baby. AWS is the space between design elements, in contrast to Passive White Space (PWS), which is the space around a design. Design practitioners believe AWS improves visual clarity of a design’s structure and layout as well as enhanced perceptions of minimalism and sophistication (Sharma & Varki, 2018).



Figure 24: Logo design for Miscarriage Corner

### 4.3.2 Design Guidelines

I designed a series of guidelines that will allow me to apply the design principles consistently, and make sure every element is employed to meet users' needs.

**a. Colour Palette**

Green, blue and purple were chosen as the main colour palette for the interface. Green is associated with nature, which provides calmness, relaxation and refreshment. Green and blue are also associated with positive content (blue, e.g., openness, peace) and (green, e.g., success, hope) (Elliot & Maier, 2014). In contrast to green, purple is rarely found in nature and provides good contrast and creates intrigue. Purple is often associated with wisdom, bravery and spirituality (Cherry, 2005). In addition, a study conducted by Bonnardel et al. shows green, blue, purple and pink are the most popular colours with women. The study highlights the similarity of choices in different cultures, with differences in warm and shade colours of purple and pink. (Bonnardel et al., 2017). The use of pink was avoided because it is often stereotypically used to refer to women.



*Figure 25: Miscarriage Corner interface colour*

**b. Typography**

Poppins is a geometric sans serif typeface with a high level of legibility. As the primary target audience of the application are immigrant women, it is essential to use a simple and easy to read typeface. Clear communication is crucial for this mobile application, and using a readable typeface provides the primary base of the design.



Figure 26: Miscarriage Corner interface typeface

### c. Illustrations

Based on the interviews with user experience designers, illustration is one of the best ways to communicate with women from different languages. Using visuals through illustrations can be more effective in communication rather than using text. I also created diversity in the illustrations of women, by having them with different hairstyles, skin colours and different clothes. Based on the interview with user experience designers, this approach helps users from different cultures feel more connected and included with the application since people from different ethnicities are involved in the illustrations.

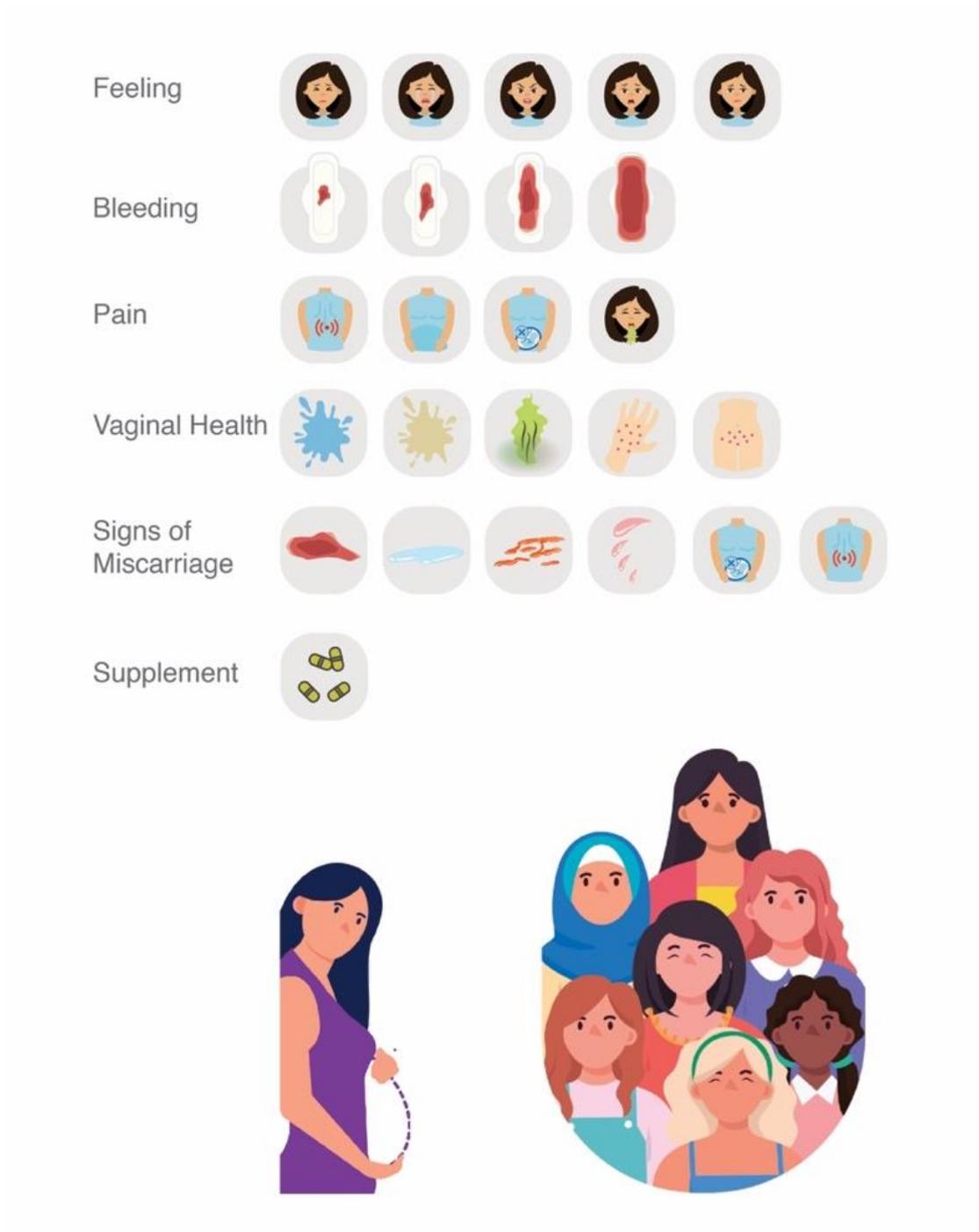


Figure 27: Miscarriage Corner interface illustrations

### 4.3.3 Sitemap

A sitemap was created to show the application's organization and the relationship between different pages. Creating a sitemap helped me figure out the hierarchy of information and the application's goals and purposes. Figures 28 to 32 show the user flow of *Miscarriage Corner*:

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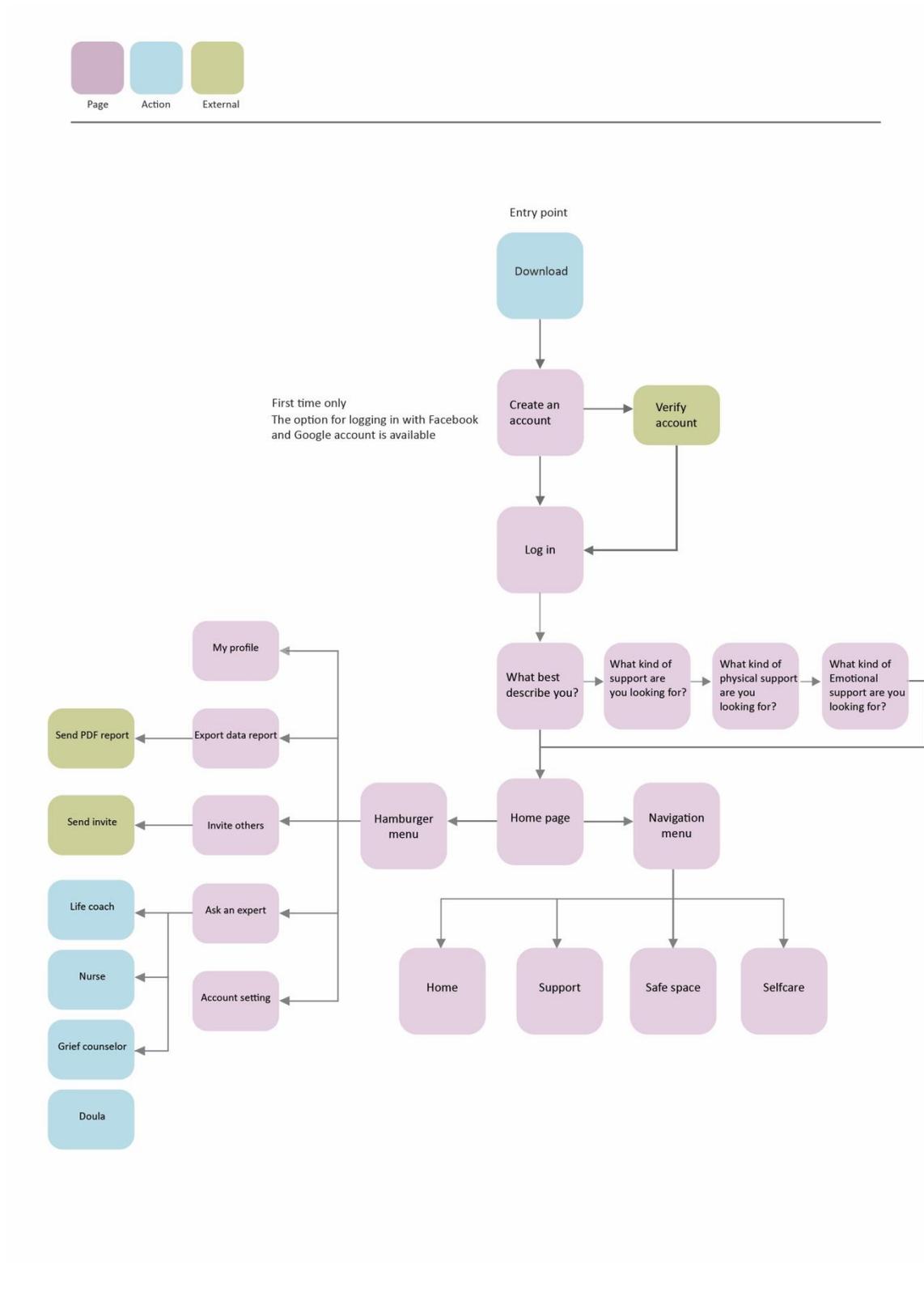


Figure 28: Part I, Application sitemap

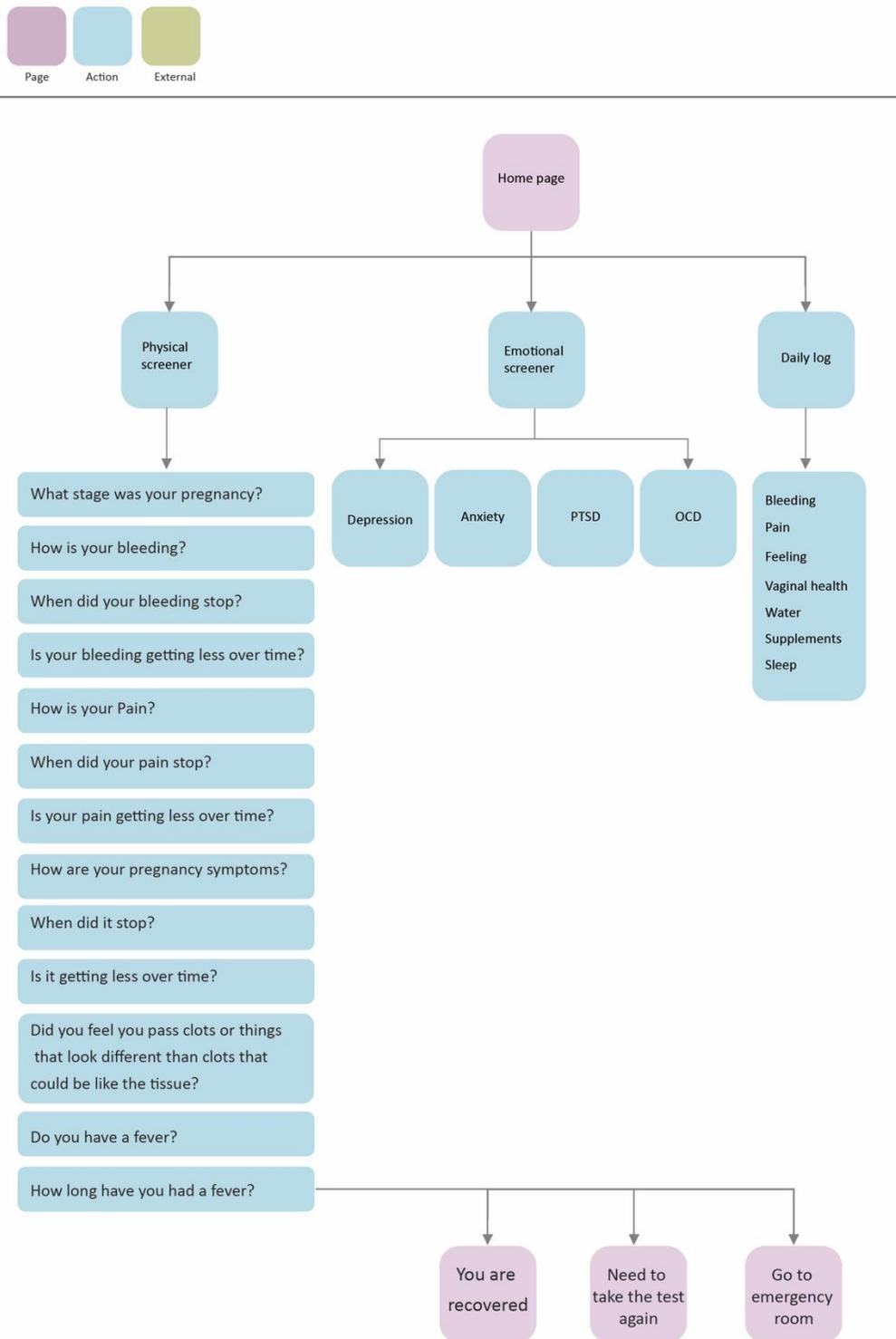


Figure 29: Part II, Application sitemap

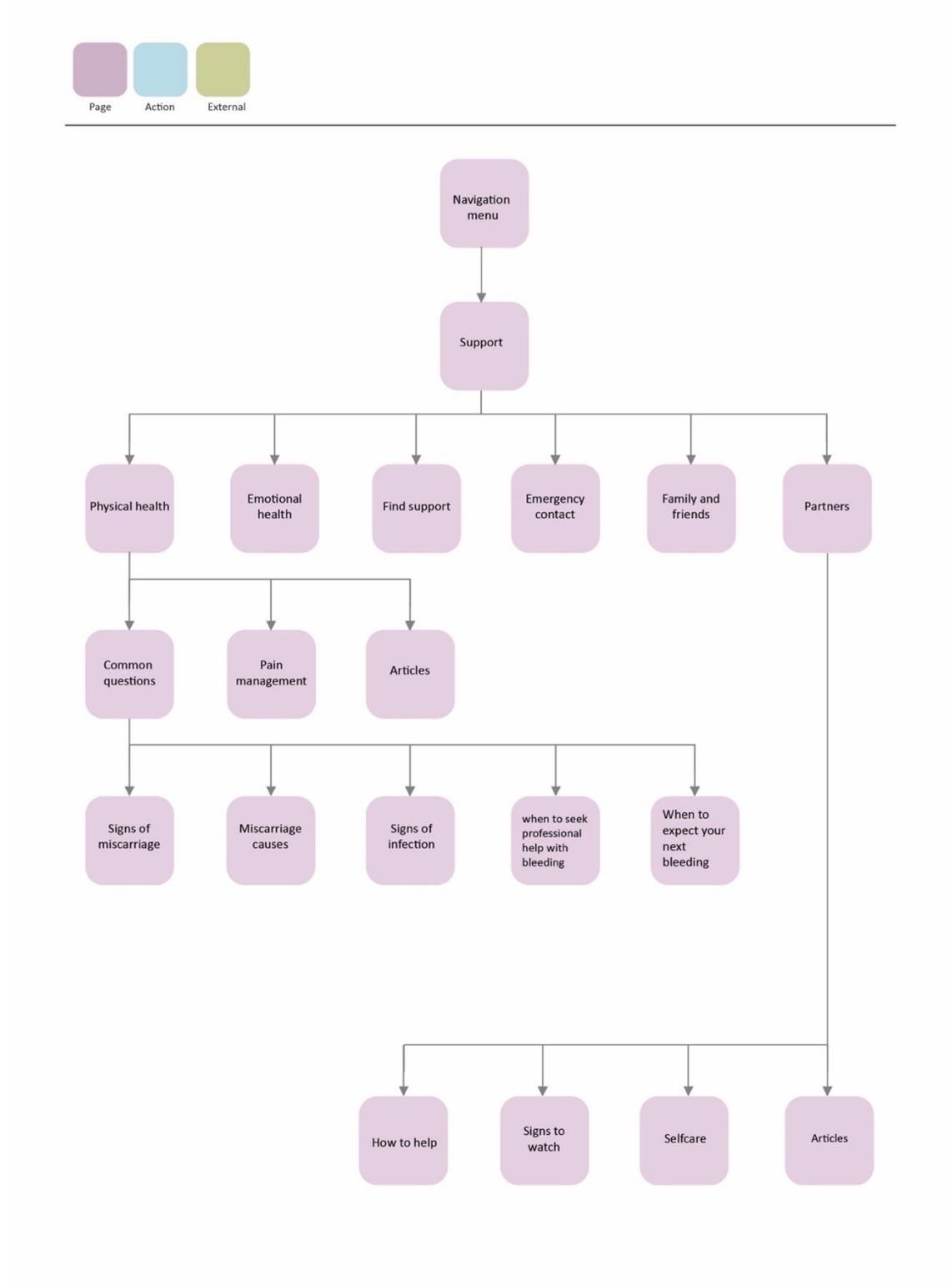


Figure 30: Part III, Application sitemap

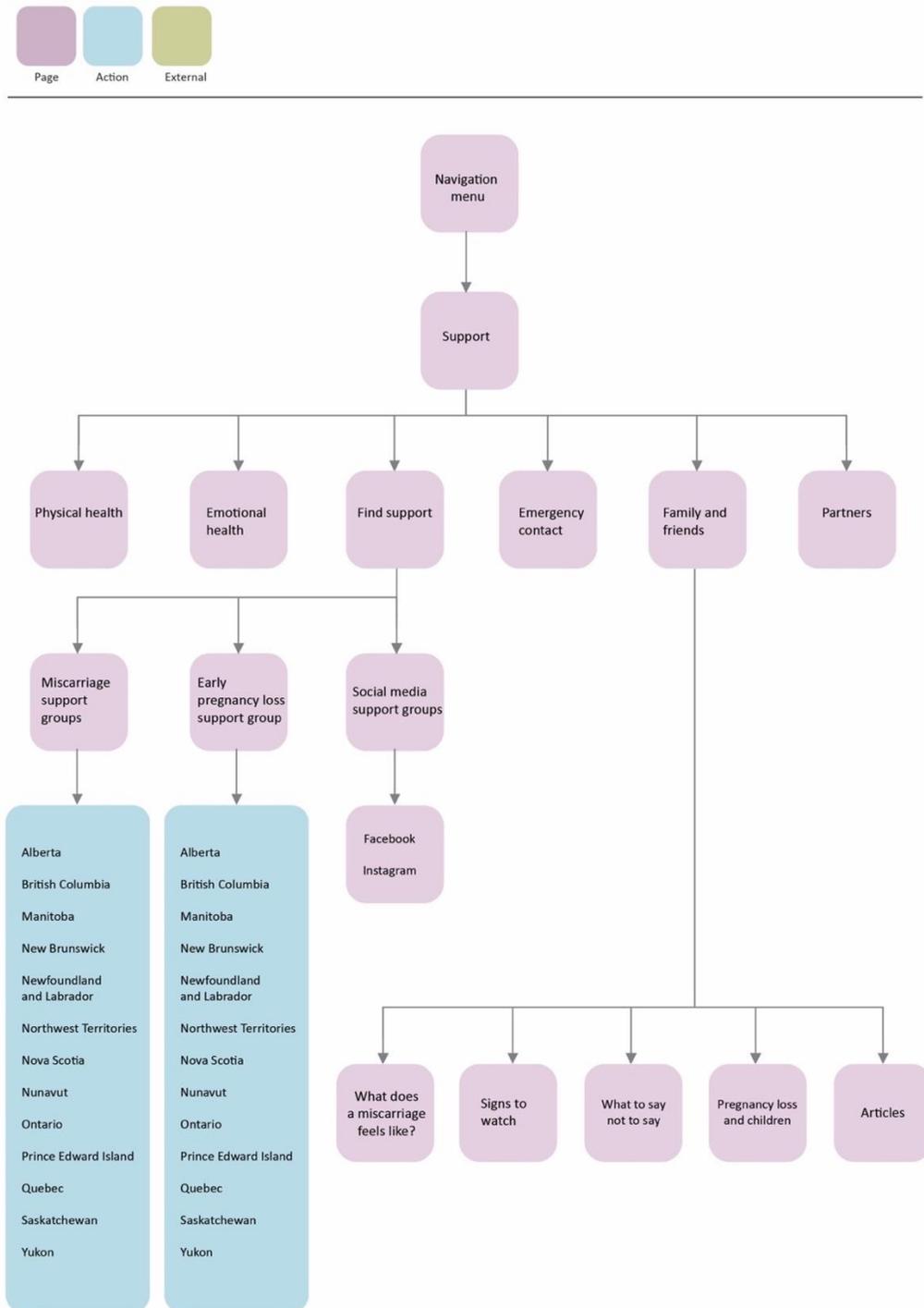


Figure 31: Part IV, Application sitemap

## Chapter 4: Design Outcome

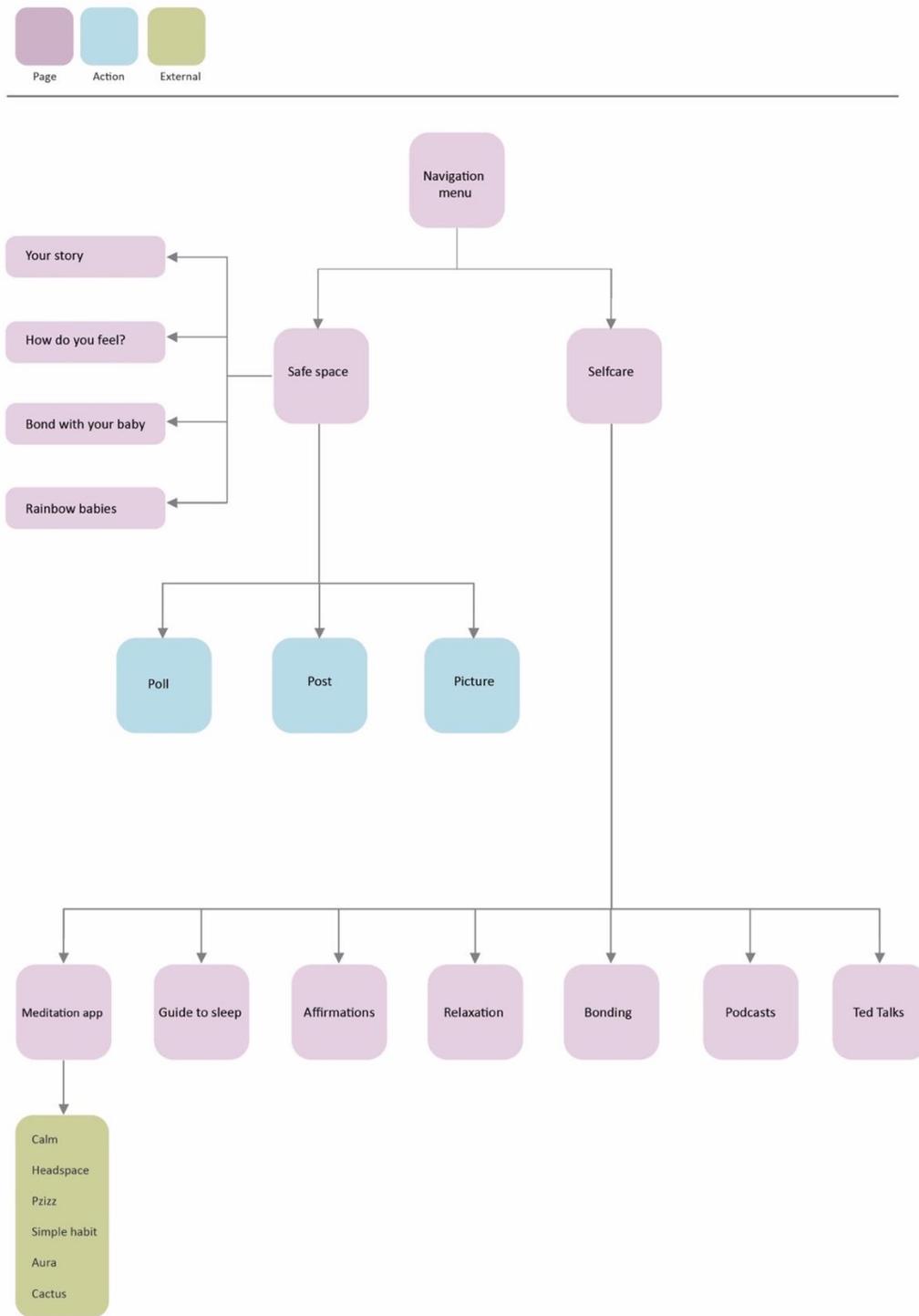


Figure 32: Part V, Application sitemap

#### **4.3.4 Wireframes**

A wireframe is a layout of a product that shows the key elements of the design on the main pages. Creating a wireframe is mostly done in the third stage of design thinking (create). It is a blueprint of the page layout, function, structure and information.

Wireframes let the designer visualize the idea in the early stage in the design and share it with stakeholders and users to receive feedback. (Designerrs, 2021). There are two levels of fidelity for the wireframes: low fidelity and high fidelity. Fidelity refers to the level of details and functionality that a prototype illustrates. Low-fidelity prototypes are simple and low-tech concepts and high-fidelity prototypes show more details and functions of the application. I created a series of wireframes to visualize the content and functionality of the application. The figure shows a set of low-fidelity wireframes designed for the Miscarriage Corner application.



Figure 33: Application wireframes

### 4.3.5 Prototype

Prototyping is one of the most important stages in design that lets designers explore various approaches from an idea before deciding the final design approach. A high-fidelity wireframe can be shared with end-users to test the designs before developing the product. It helps the designer catch any design issues at an early stage and revise them. I created a set of high-fidelity prototypes on *Figma* to first visualize all possible concepts, and second share and test them with immigrant women through usability testing. *Figma* is a cloud-based design program that allows the designer create high fidelity prototypes and has the capacity to share the prototype links with others. The program lets users add their comments and feedback to each page while providing designers with the flexibility to make easy edits and refinements to the application.



Figure 34: Prototype of a user using Miscarriage Corner on a mobile

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To give the user a customized experience, a couple of questions will be asked prior to entering the application. These questions include: What describes your situation best? What are your support goals? What kind of physical support are you looking for? What kind of emotional support are you looking for? etc. By answering the questions, the sections that are fits with what the user needs will be provided for them. **Figure 35** shows the process of entering the application.

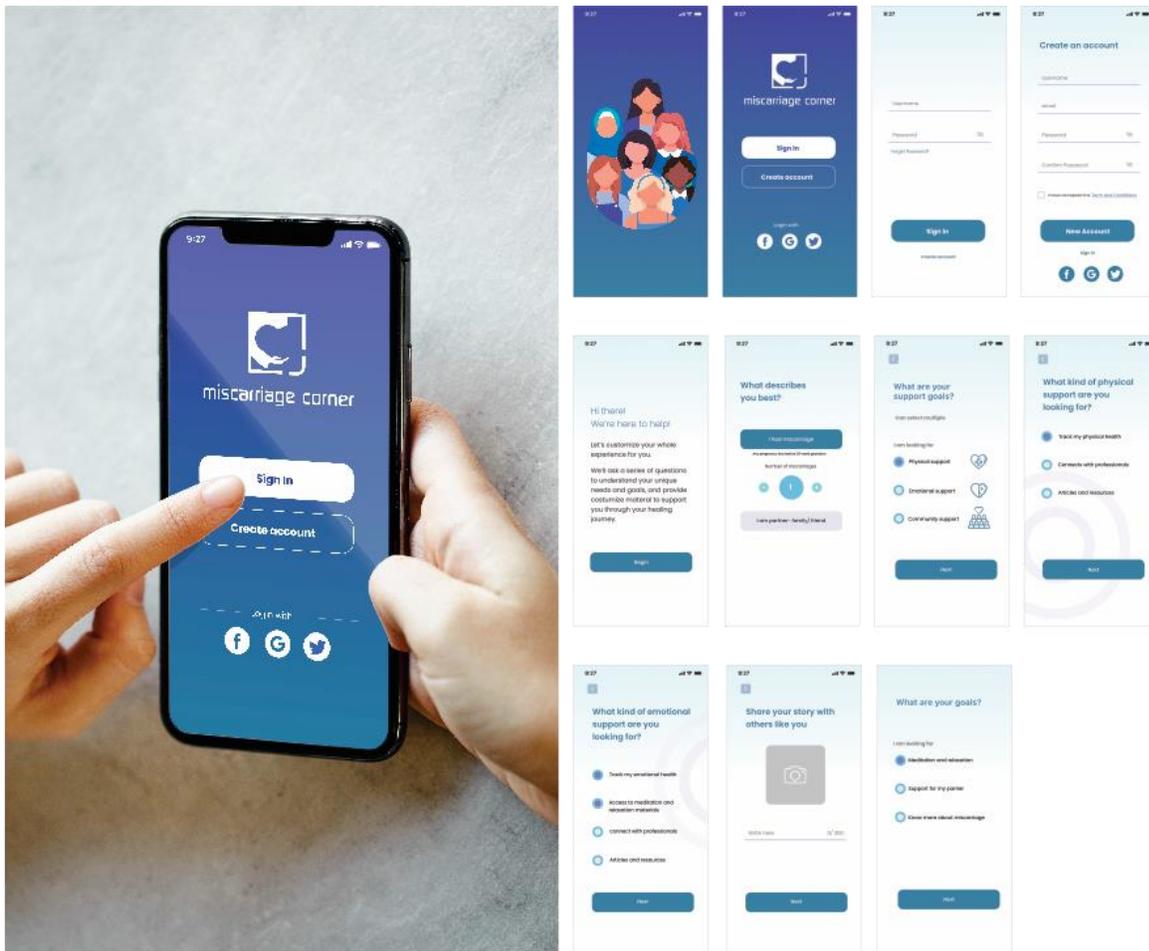


Figure 35: Landing page

There are four components on the main page:

**a. Navigation Bar**

The navigation bar links the user to different sections of content through the application. The navigation bar in *Miscarriage Corner* has four sections:

**a.1 Home**

The *homepage* is the first page users see when entering the application. The different sections of the application are accessible on the first page. Based on data analysis from interviews and co-design session with experts normalizing the experience, helping women know that a miscarriage is not their fault and providing physical and emotional support is essential content to share on the first screen. As a result, the following four sections were added to the main page: *20% of Pregnancies end Miscarriage, This is Not Your Fault, Physical Health and Emotional Health*. Providing this information on the Homepage helps the user get the most important information in the first encounter with the application.

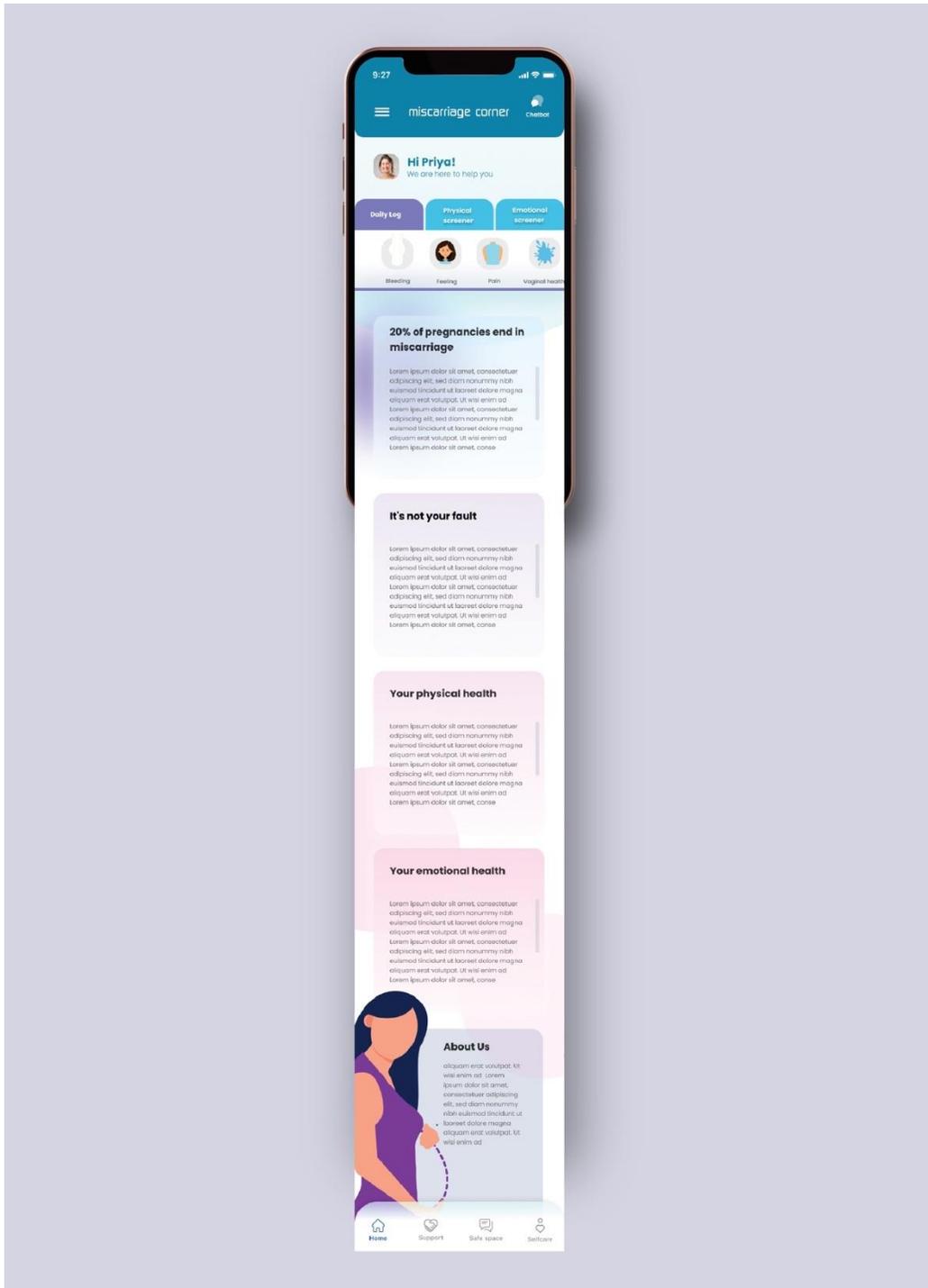


Figure 36: Homepage

The main page has four action buttons:

#### **a.1.1 Physical Screener**

As Tam mentioned, a physical screener can help women know in what stage of miscarriage they are (Chapter 3: Qualitative analysis), with the screener reducing the need to go to an emergency room. If the user says no to fever, pain, bleeding and pregnancy symptoms we can make sure the women are past their miscarriage physically successfully. The *screener on Miscarriage Corner* asks the users a series of questions to let women know if they have passed their miscarriage successfully, need to take a test again in a couple of days, or need to go to an emergency room immediately.

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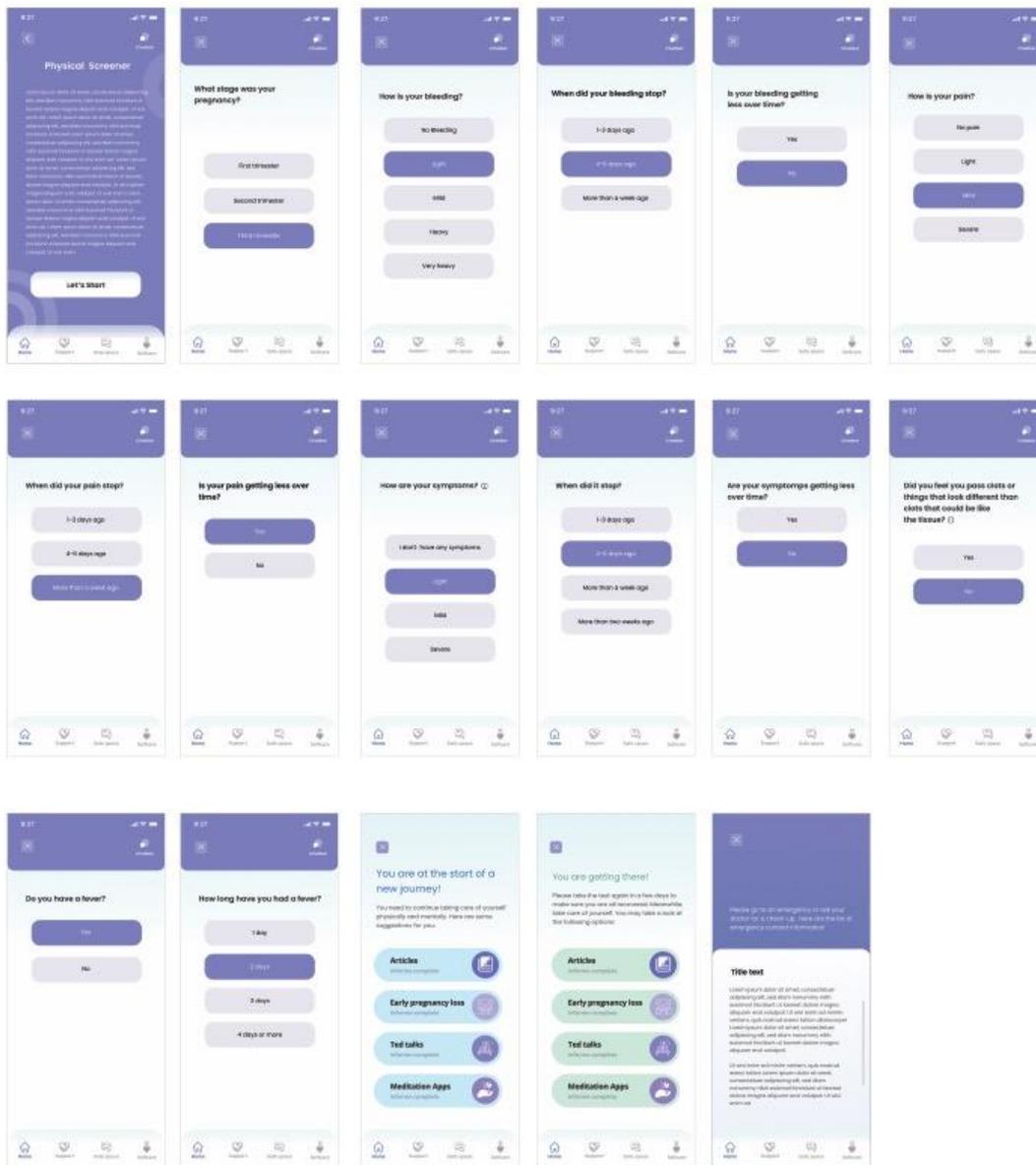


Figure 37: Physical Screener

### a.1.2 Emotional Screener

Aanderson believes an emotional screener is an effective way to evaluate the mental well-being of women after a miscarriage. An *emotional screener* is a simple tool which can detect if the user is experiencing anxiety, depression, OCD, etc., based on the user's answers to a few questions. It follows an algorithm provided by Kristine Aanderson, a psychologist who participated in an interview and the co-design session. Answering a couple of questions such as; how are you feeling? And then if it's sad, has it been more than two weeks or less than two weeks of every day or almost every day? Or anxious? Has it been interfering with your ability to do regular things in your life? The screener can refer women to grief groups or psychologists if needed. It should be noted that the screener is not a substitute for being evaluated by a professional psychologist. The screener could work as a reminder for women to take care of their mental health and seek help if they do not feel well emotionally. **Figure 38** shows an example of questions for detecting depression. The same was designed for anxiety, PTSD and OCD.

#### a.1.2.1 Depression

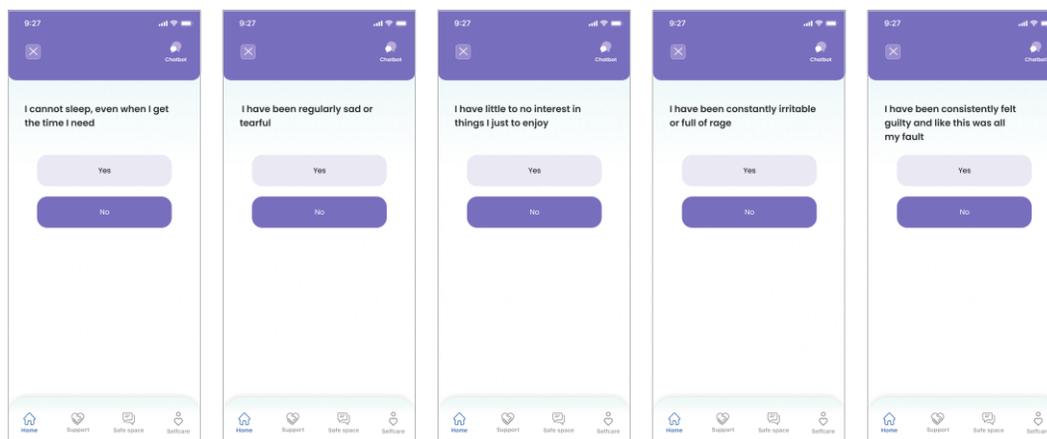


Figure 38: Emotional Screener/Depression

### **a.1.3 Daily Log**

A *Daily Log* is a tool used to assist women in documenting physical symptoms of a miscarriage such as bleeding, pain, vaginal health, water intake, emotional state, sleeping habits, exercise and supplements taken. After a miscarriage, it is essential for women to take good care of themselves physically and emotionally, whether or not they want to get pregnant again. A *Daily Log* can also help as a reminder to take care of themselves and monitor their progress. In addition, all information from *Daily Log* can be exported and sent through email to healthcare providers.

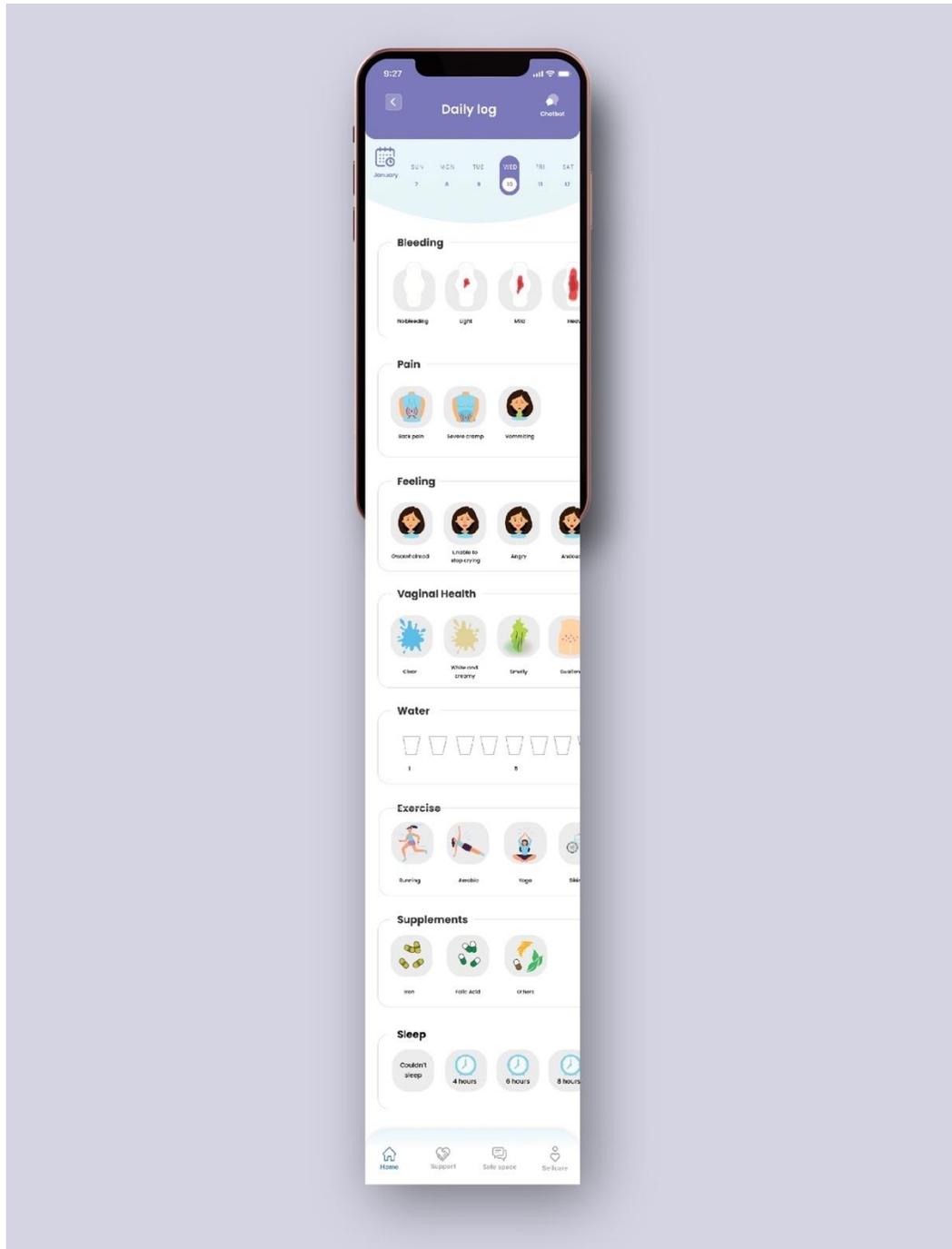


Figure 39: Daily Log

#### a.1.4 Chatbot

A *chatbot* is an artificial intelligence (AI) software program that lets the user seek immediate support through the application. The *Chatbot* helps provide users the support they need depending on the areas they require support with, such as physical support, emotional support, and access to resources, talking to experts, etc. This helps improve the interaction between women and the application by providing customized support for their needs, which enhances the quality of the user experience.

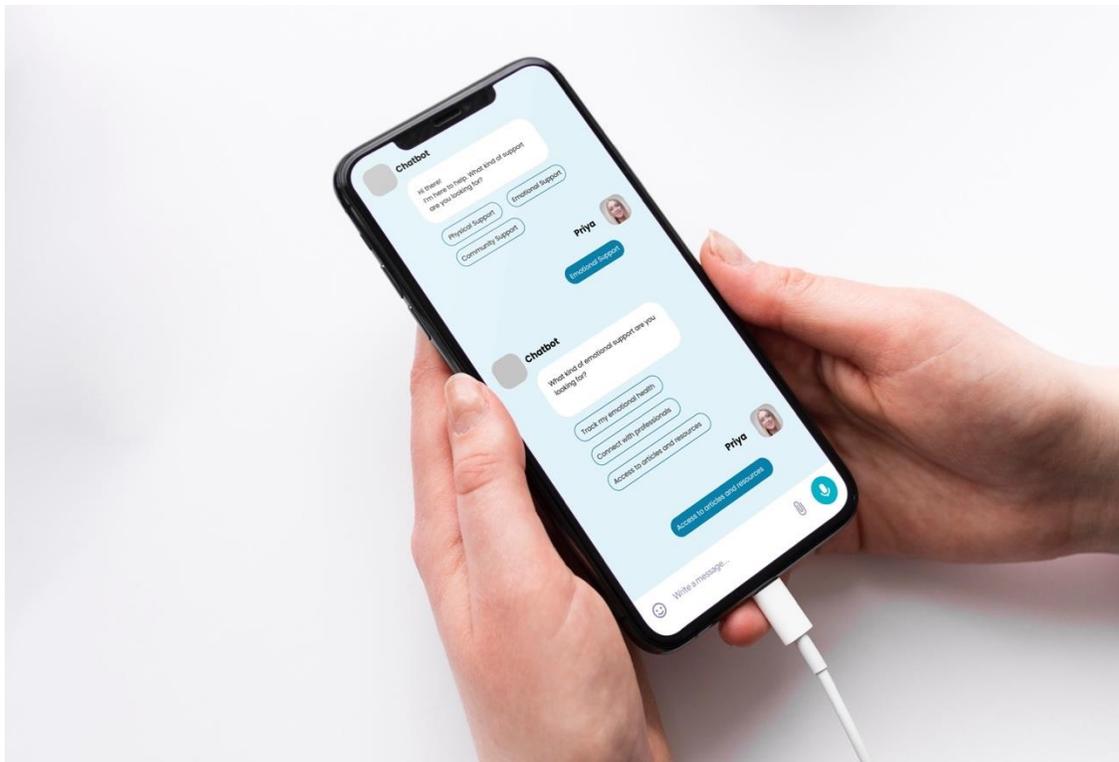


Figure 40: Chatbot

## a.2 Support

The support section helps users find the resources they need to provide support for themselves physically and mentally.



Figure 41: Support

This section has six subsections as follow:

### a.2.1 Physical Health

There are three areas under the *Physical Health* section of the site: *Common Questions*, *Pain Management* and *Articles*. The section *Common Questions* has answers to the frequently asked questions women may have after a miscarriage; such as what are the signs of infection, what are the signs of miscarriage, when to seek professional health with bleeding, etc. The section *Pain Management* offers users information on how to manage their pain and

## Chapter 4: Design Outcome

when to seek further help. Lastly, the section *Articles* links the users to a series of online articles about physical health after a miscarriage. Women can search through a database and find what information is applicable to their needs.

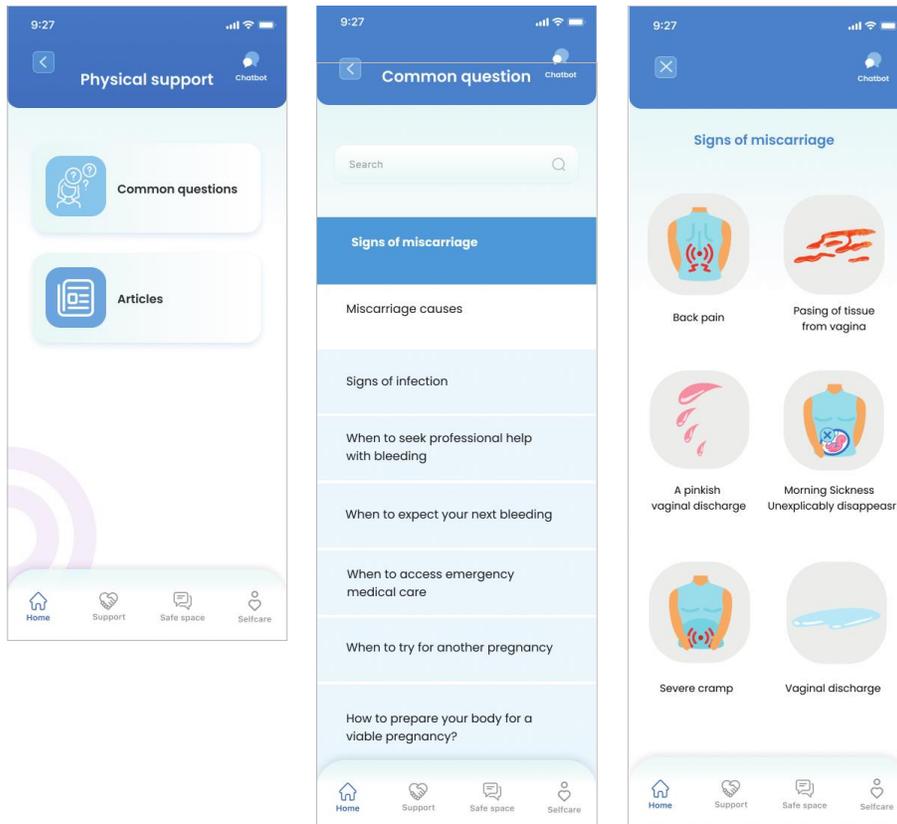


Figure 42: Physical Health

### a.2.2 Emotional Health

*Articles* and *Mental Health Support Services* can be found in this section. The information will be categorized by province.



Figure 43: Emotional Health

### a.2.3 Find Support

Information about *Early Pregnancy Loss Program*, *Miscarriage Support Group* and *Social Media Support Groups* can be found under this section. The users can search for specific information for the province they live in.

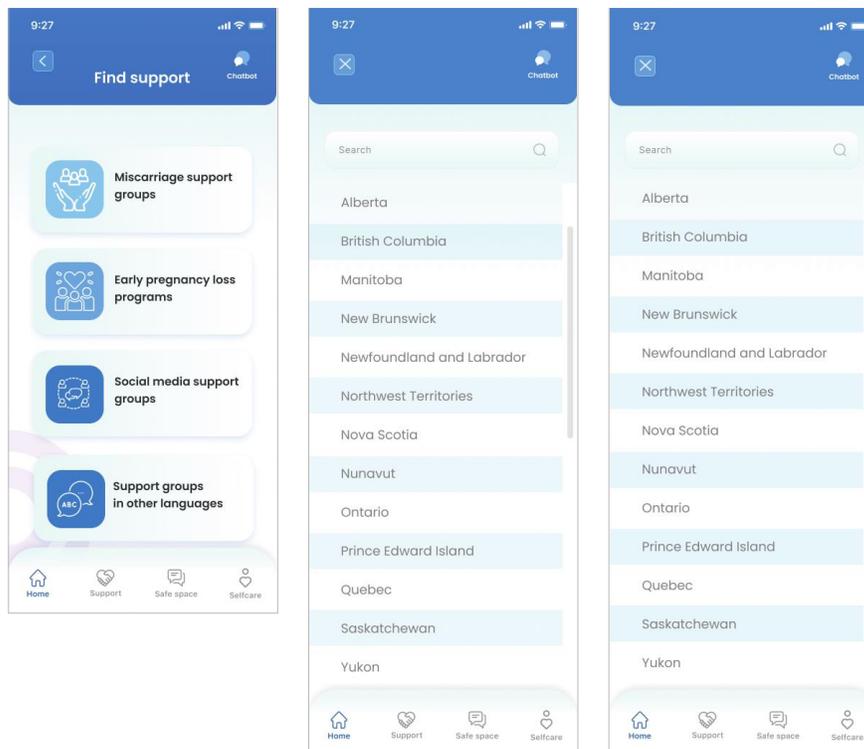


Figure 44: Find Support

### a.2.4 Emergency Contact

This section provides all the emergency contact information for each province. The importance of providing emergency contact information for women was discussed during the co-design session and interviews with experts.

### a.2.5 Family and Friends

According to Walker, it is important to involve families and friends through the healing process and help them find the best way to support their loved ones after a miscarriage. Understanding what a miscarriage may feel like, what to avoid saying, how to sympathize, how to help, and what signs to watch are some of the information provided in this section. There is also a section for children and pregnancy loss that provides information for how to explain pregnancy loss to children through stories, painting, etc.

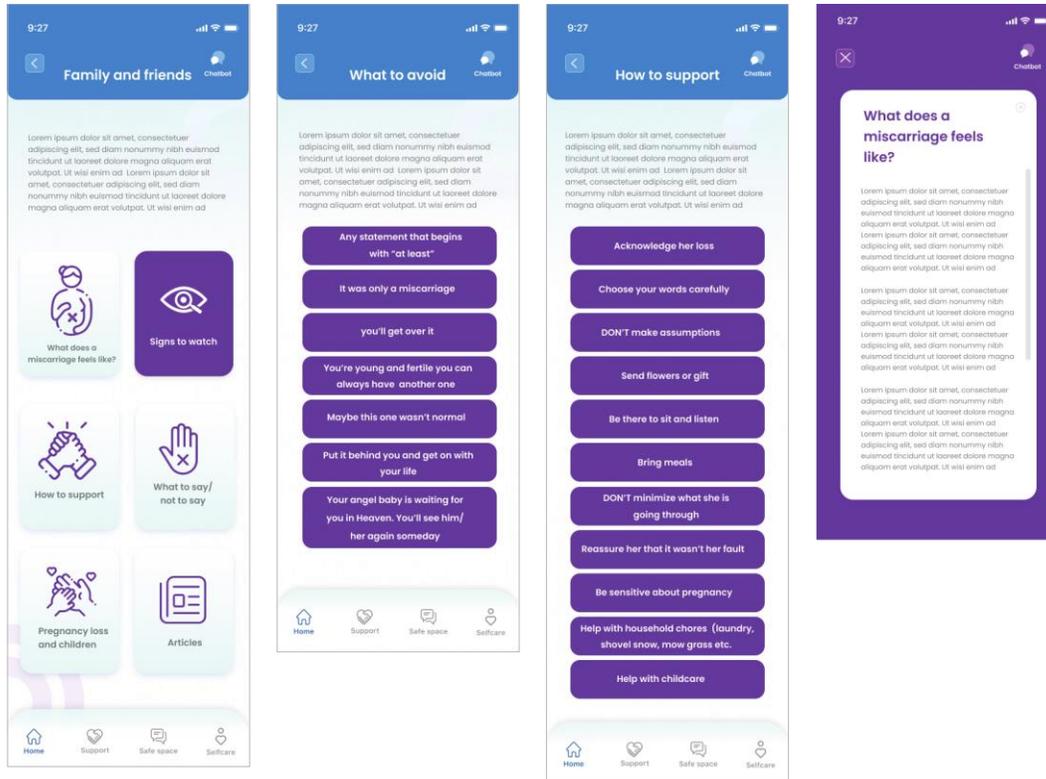


Figure 45: Family and Friends

### a.2.6 Partners

The birthing women are not the only parent affected by a miscarriage. According to Gill, the application needed to have a section for partners and support them through a miscarriage as well. This section has the following subsections: *How to Help*, *Signs to Watch*, *Selfcare* and *Articles*. *How to Help* and *Signs to Watch* help partners know how to support their loved ones. *Selfcare* and *Articles* support partners through the miscarriage if they are affected and need individual help.

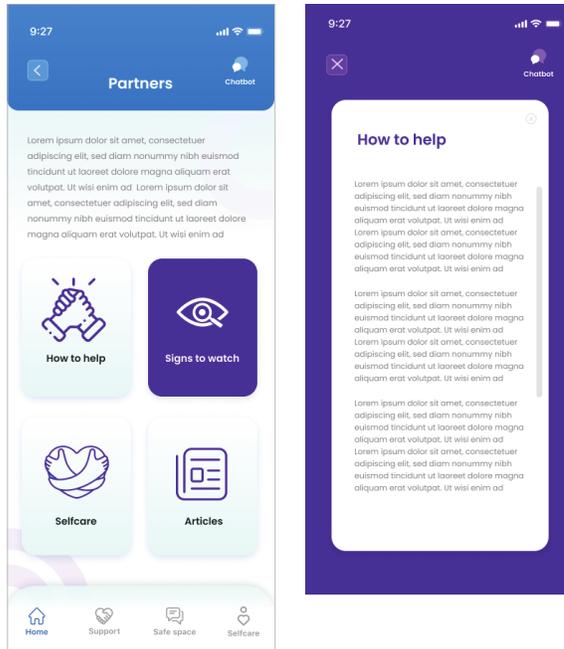


Figure 46: Partner

### a.3 Safe Space

*Safe space* is a chat platform with several rooms (your story, bond with your baby, etc.) that provides a safe space for women to share their feelings and support one another. Women can ask questions or concerns they may have, post what they are going through and talk about their feelings with other women going through a similar experience. Based on research women progress better when they are able to see other women with similar experiences, who are ahead in their recovery journey. It helps provide hope and makes them feel less lonely when they see other women experiencing a miscarriage and recover. This section also helps build the community aspect of the application, by connecting women with similar experiences.

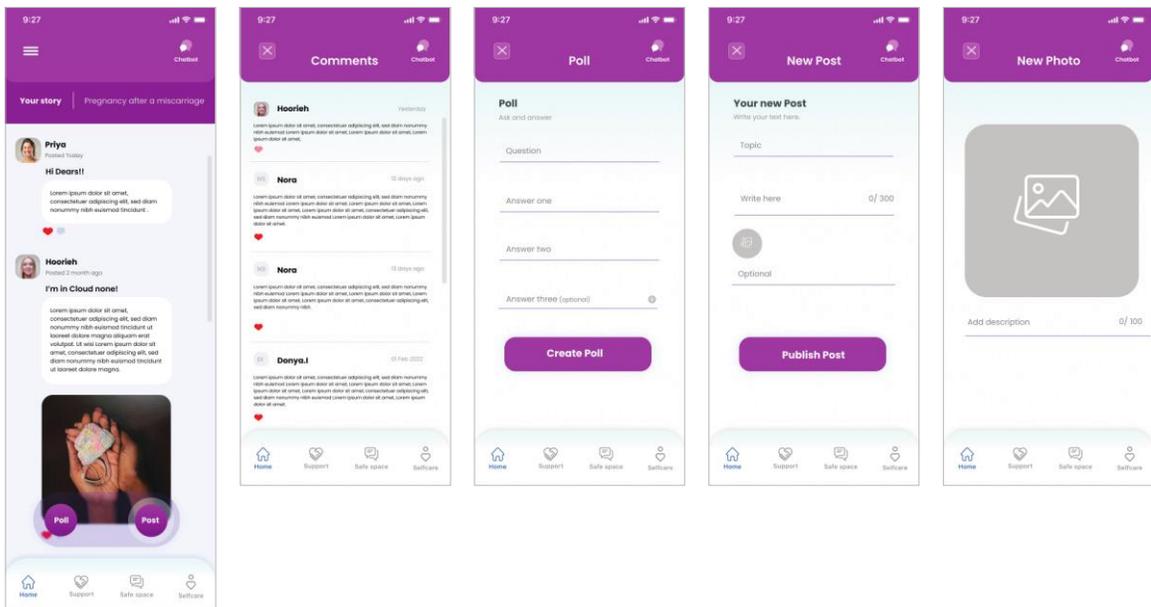
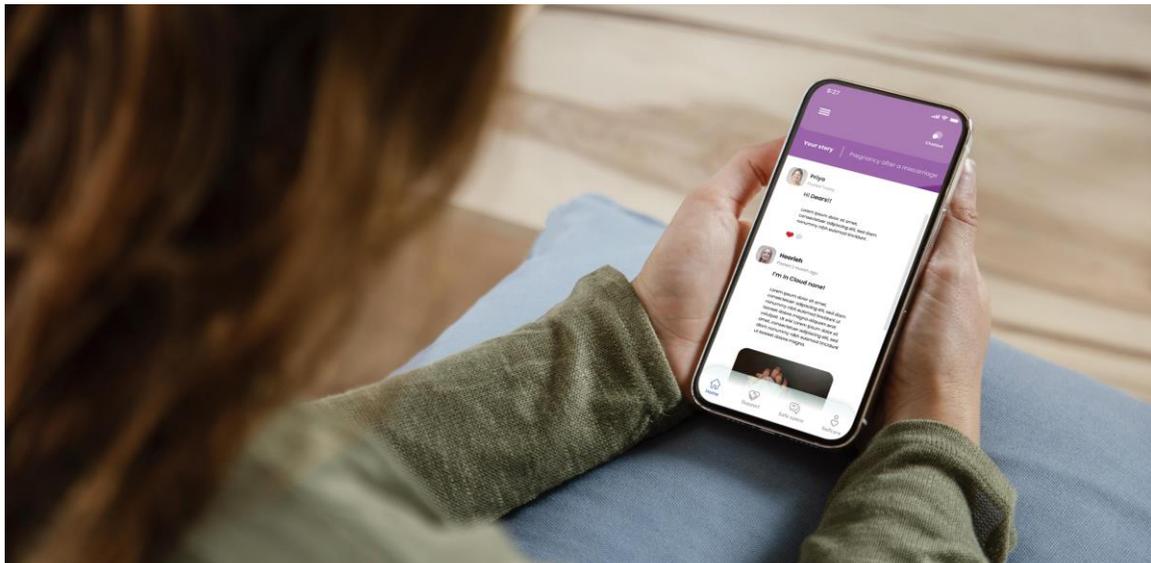


Figure 47: Safe Space

#### a.4 Selfcare

Research shows many women experience anxiety, stress and depression after a miscarriage (Chapter 2: Literature review). In the co-design session, Aanderson

## Chapter 4: Design Outcome

talked about the “Two AM phenomenon”. She believes this is the time when women do not have to take care of other family members and start thinking about their miscarriage. In-person support will not be available at this time of the day and providing resources for women to reach out is a great way of helping them. The section *Selfcare* provides resources for women to help themselves through this hard time.

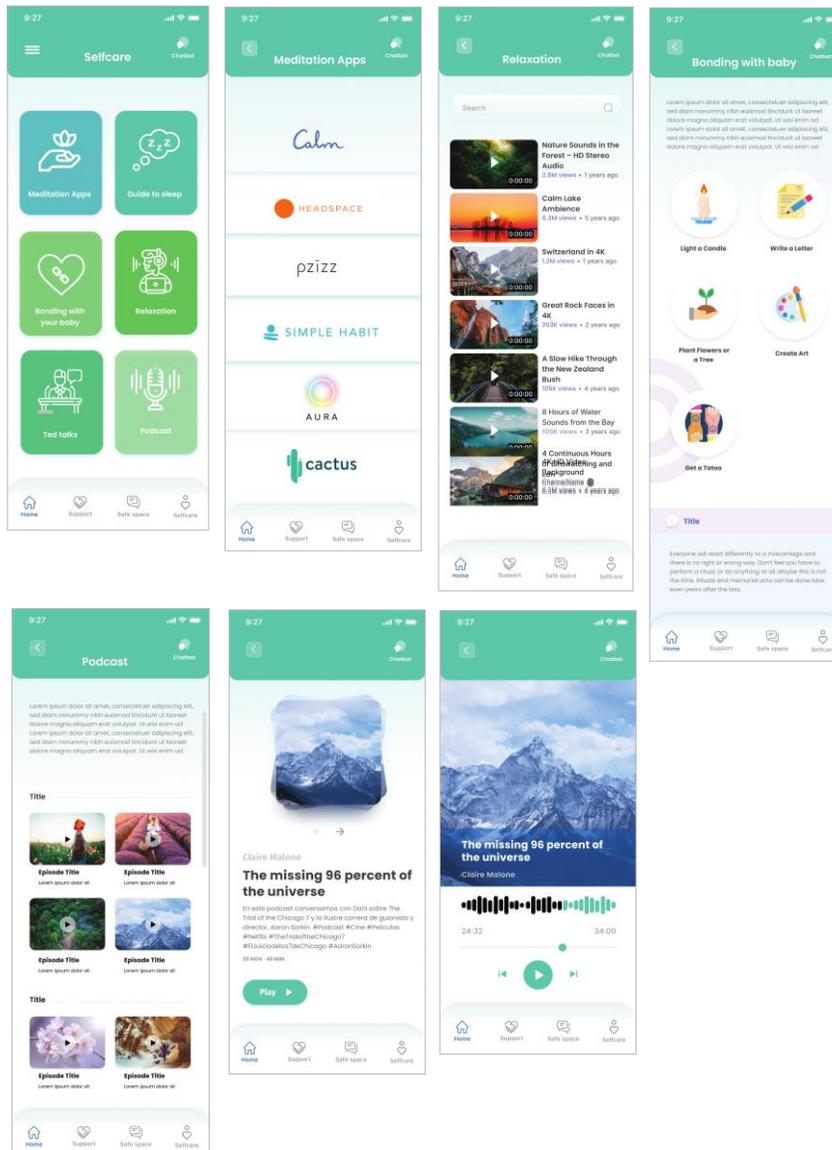


Figure 48: Selfcare

The section has the following subsections:

#### **a.4.1 Meditation Apps**

This section connects the user with meditation applications. By clicking on each logo, the user will be transferred to the download page on the App Store or Google Play.

#### **a.4.2 Guide to Sleep**

Based on data analysis, women may find it hard to sleep when they are experiencing depression. This section connects women to sleep guide material.

#### **a.4.3 Relaxation**

The use of nature has a positive impact on women's emotional well-being, Aanderson noted. This section provides calming videos of nature to help the user feel more relaxed and in control of their feelings.

#### **a.4.4 Bonding with Baby**

Data analysis shows continuing bonds with babies help women acknowledge their loss and feel better. This session gives women some ideas of how to continue their relationship with their babies.

#### **a.4.5 Podcasts**

This section provides a series of podcasts related to loss and miscarriage for women.

#### **a.4.6 TED Talks**

Based on the data analysis, women feel better if they know about other women's stories. This section links women to a list of TED talks about miscarriage.

#### **b. Hamburger Navigation**

*The Hamburger Menu* is a button on the app that opens a side menu. Visually, it is three horizontal lines that resemble a hamburger. Based on the interview with UX designers, it is essential to have the lowest level of learnability required while designing for health. The hamburger menu is a universally understood sign and users can recognize it easily. In addition, *the Hamburger Menu* is easy to detect by people from different languages. I used a hamburger menu to shift the secondary options from the main menu (Navigation bar) to a hidden sidebar.

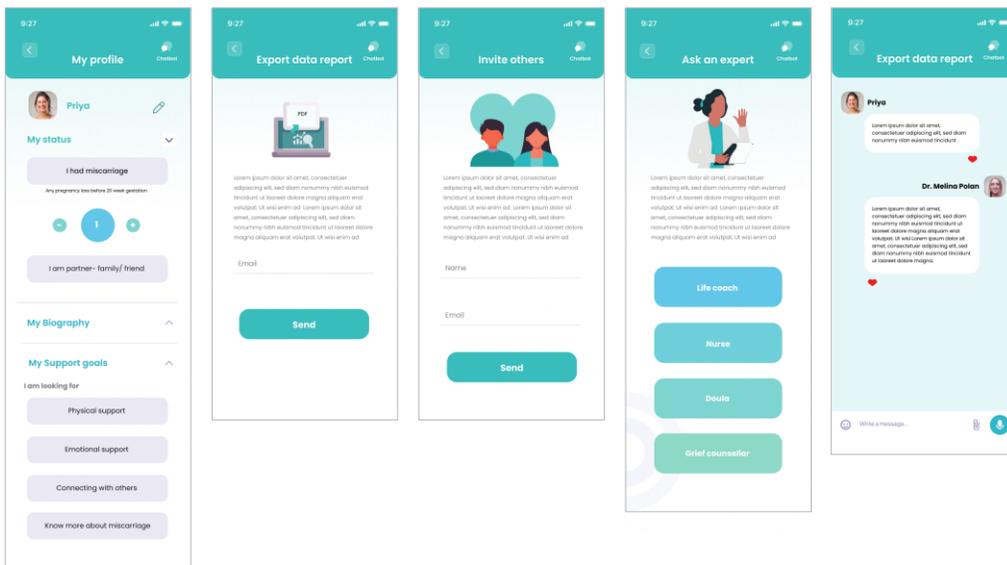
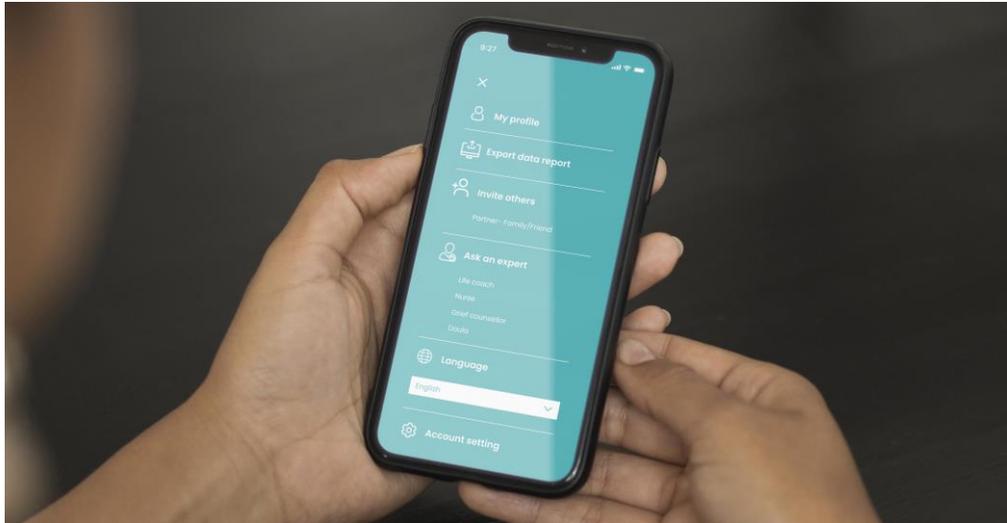


Figure 49: Hamburger navigation

There are five sections on the hamburger menu:

### b.1 My Profile

In this section, users can set their status (I had miscarriage/I am partner, family/friend) as well as enter the number of miscarriages they have experienced. They can also write a short biography of themselves and set their

support goals. This setting lets the application provide a customized experience for the user.

### **b.2 Export Data Report**

The data entered into the daily Log will be transferred and analyzed through easily accessible infographics. Providing this data in an easy to understand format, will help users track their progress and recognize areas for improvement. The user is able to send this PDF to themselves or healthcare providers through email.

### **b.3 Invite Others**

Women are not the only people who need support or knowledge about a miscarriage. This feature lets the user invite partners, family and friends by sending them a link to the application via email.

### **b.4 Ask an Expert**

Based on data analysis from the interviews and co-design session with experts, providing an opportunity for women to talk to experts, can help them trust the information and feel more secure. This section allows the user to connect with life coaches, nurses and grief counsellors.

### **b.5 Account Setting**

*Account Setting* gives the user access to the sign-up information and security set up.

## **4.4 Usability**

Usability can be described as the capacity of a system to provide a condition for its users to perform the tasks safely, effectively, and efficiently while enjoying the experience (Lee et al., 2019). In this study, I employed user testing to get immigrant

women to interact with the application and observe their behaviour and reaction to it. User testing helped me find areas of confusion, uncover opportunities to improve the application and learn about immigrant women's behaviour and preference. User testing is a good way to determine if the user:

- Does not get lost in the application
- Can finish the assigned tasks
- Does not encounter technical issues
- Enjoy their experience

### 4.4.1 Participants

Three immigrant women from the Philippines, India and Iran participated in the study to evaluate the usability of the apps. Faulkner (2003) expresses that even a small number of participants are able to reveal a great number of problems and errors in tests and just five participants can help researchers find 99% of the problems. Participants that reviewed the app were between 18 to 44 years old, have had a miscarriage in the last five years, and could communicate in English.

### 4.4.2 Usability Method

A combination of qualitative and quantitative usability testing methods was employed to identify the problems and issues of the designed prototype. The participants were asked to share their screens during the session (sessions were conducted online). As part of qualitative user testing, participants were asked to browse the application while commenting on the feature, flow, UI, etc. In this method, the researcher is able to ask follow-up questions to get insight into the issues that users are facing (Budiu, 2017).

In addition to qualitative analysis, a quantitative analysis was conducted to evaluate the design's effectiveness and efficiency. In quantitative usability testing the

## Chapter 4: Design Outcome

participants were given a series of tasks while thinking aloud (i.e., expressing their opinions, thoughts, anticipations, and actions) during the test. As a widespread method of usability testing, thinking aloud provides the researchers with the ability to discover what users think during task performance and completion (Georgsson & Stagers, 2015). It gives the researcher the ability to observe the process and take notes. The researcher is able to ask follow-up questions about the reasons behind the user's decisions. The researcher is able to see what participants are struggling with while finishing the assigned tasks and infer which parts of the design are problematic and which function properly (Budiu, 2017).

To examine the quality of how well tasks were fulfilled by the users (Georgsson & Stagers, 2015), the ISO 9241-11 framework was employed. There are three components in the framework: System Effectiveness to examine the users' ability to complete the given tasks, System Efficiency to examine the required user resources to complete the tasks, and System Satisfaction to record the users' opinions and feedback (Constantinescu et al., 2018).

Effectiveness	the accuracy and completeness with which specified users can achieve specified goals in particular environments
Efficiency	The resources expended in relation to the accuracy and completeness of goals achieved
Satisfaction	the comfort and acceptability of the work system to its users and other people affected by its use

Table 7: Components of usability testing based on ISO 9241-11 (Moumane et al., 2016. P.4)

**System Effectiveness:** Participants were asked to complete seven tasks, and the success or failure rate of completing each task was measured to evaluate the app's

efficiency. Task completion was considered successful when the user completed the task without producing an error or asking for assistance.

**System Efficiency:** For evaluating system efficiency, the researcher recorded the time (in seconds) that participants took to complete each task. Each task was initiated by expressing the word “start” and finished when the user mentioned the end. Upon completing each task, the users were asked to fill out the Single Ease Questionnaire (SEQ) to examine the level of task difficulty. The questionnaire is a seven-point Likert scale in which scale 1 indicates the task as “very difficult”, and scale 7 indicates the task as “very easy” (Constantinescu et al., 2018).

**System Satisfaction:** System satisfaction is used to evaluate the overall usability of the apps through the System Usability Scale (SUS), which is a usability assessment questionnaire with reliable and valid results. It includes ten questions, each with five items ranging from “strongly agree” to “strongly disagree”. The score range is from 0 to 100 and scores higher than 80 are considered high usability while those below 70 are considered low usability (Georgsson & Staggers, 2015).

#### 4.4.3 Tasks

Seven tasks were selected based on the importance of features from the co-design session with experts. Prior to the test, the participants were informed and asked to provide information on each task. The tasks were as follows:

1. Add to *Daily Log*
2. Find the section for partners
3. Find physical support
4. Add comments on the chatroom
5. Find the link to meditation applications
6. Listen to podcasts

## 7. Export PDF data

### 4.4.4 Procedure

Prior to the test participants were informed about the aim of the study, and how the test will be conducted. They were asked to express their honest opinion throughout the test, and express their feelings, thoughts and ideas without censoring themselves. The test was conducted online on Zoom. The whole section was recorded. The participants were asked to complete seven tasks on each application while engaged in a thinking aloud method. The testing procedure took approximately one hour for each participant. After each task, participants were asked a series of follow-up questions. When the test is over, the participants were asked to fill out SEQ and SUS questionnaires to measure the efficiency of the apps and their levels of satisfaction. **Appendix 4** shows the SEQ and SUS questionnaire.

### 4.4.5 Results

#### 4.4.5.1 Qualitative analysis

##### Participant A

Participant A is 40 years old. She is originally from the Philippines, she moved to Canada when she was 11. She had a miscarriage a few months ago while five weeks pregnant. Participant A is pregnant again and in her fifth week of pregnancy.

The purpose is to provide a place for those who have had a miscarriage to go and find resources, but also know that they can be very well supported physically and emotionally, and yeah, I think it is great. It is a very good app.

—Participant A

Participant A found the application easy to navigate, simple to follow and informative in the content provided. She was able to finish all tasks of the user testing without being confused or lost. She liked the overall look of the application, from the logo design, colour palette, information architecture etc. She connected with the name of the application *Miscarriage Corner*, however she wasn't sure about having "miscarriage" as part of the name of the application, since women may not want to have it as an icon on their phone. If the name of the application is more indirect, it could be easier for women to use the application in a more public setting, such as a public park or when they are commuting through public transport etc.

Participant A believe it was easy to navigate through the application to find what you need and understand what each section is about. The only section she struggled with was the section for partners and family and friends. She was slightly confused on if that section was meant for how she could help her friends and family as opposed to that section being for her family and friends to help her. She recommended adding "For" to the title of the sections and changing the colours to make those sections, to make them more distinctive and obvious for the users.

Participant A talked about the challenges women may find to talk about their miscarriage to their partners. Having a section on how to talk to your partner and offering resources such as *PAIRED: how to talk about difficult topics* could be beneficial. She also believes having one miscarriage is different from having multiple miscarriages, based on her experience with friends who have had multiple experiences. Adding a separate section for women with multiple miscarriages could provide specific information for their experiences such as; "Pregnancy after multiple miscarriages, Possible risk factors after multiple

pregnancies, etc.” Also, creating a separate chat room dedicated to women with multiple miscarriages in the *Safe Space* in the application could be helpful.

Participant A also noted that using simple language, icons and easy to understand illustrations made it easier for her to navigate through the application. She liked the *Daily Log* section, and she could see herself using that feature every day. She also found the *Physical Screener* easy to use with clear and simple questions.

### Participant B

Participant B is 42 years old. Her parents are from India, but she was born and brought up in Canada. Participant B has experienced three pregnancy losses. One ectopic pregnancy, one still birth and one miscarriage at eight weeks.

I like the overall look of the app. I think it looks like it is fairly easy to navigate. There are not too many buttons. Like I said, I like the colours. This is really silly but I like that the icons here are with different colour women, not just the blond hair blue eye person, because I notice that kind of stuff and it feels more inclusive. Overall, it seems quite simple to navigate.—Participant B

Participant B found the application simple to navigate, engaging to look at and practical to use. She liked the function of the *Physical Screener*; however she found the question about *How are your pregnancy symptoms* problematic. Women who have experienced a miscarriage may find the word “Pregnancy” triggering since they aren’t pregnant anymore and it might remind them of their loss. The question could be changed to be *How are your symptoms* instead, and further information about the symptoms will be provided as a small button.

One of the problems Participant B experienced after her miscarriage was being asked by co-workers and friends about her baby and she found it very challenging to talk about her loss. She didn't know what to say and they didn't know how to respond. She found the section for family and friends very helpful for her situation, especially the information provided in the section *What to avoid saying*. She believes most people need to be taught and educated on what people should say to women who have experienced a miscarriage and how they can support them. She also suggested adding a section that teaches women how to communicate to others and how they can share their experience to make them feel more empowered in this challenging situation.

Participant B believes partners can be strongly affected by the incident as well. The section for *Partners* can be very helpful and she would invite her partner to use the application. She suggested providing links for community support groups for partners. Talking to other partners that have gone through a similar experience, would help them feel less alone.

She found the *Selfcare* section extremely beneficial. She has used three of the suggestions mentioned in *Continue Bonds* section (light a candle, healing through art and plant a tree). She found the information helpful for her and believes it would help other women who are not aware of this information. She also suggested adding *Massage Therapy and Acupuncture* as possible recommendations in the *Relaxation* section.

### Participant C

Participant C is 36 years old. She lived in Iran and immigrated to Canada ten years ago. She had a miscarriage at the eight weeks gestation a year and half ago. She was able to have a healthy pregnancy following.

Participant C found the application convenient and easy to navigate. She found the language simple to understand and the layout easy to follow. She felt confident using the application, because of the simple language and the lack of medical jargon which she often felt using other applications. She liked the overall visual look of the application. However, she found the colours a bit cold for her liking, she preferred a warmer tone of green and purple.

She believes the Physical tracker is a practical and important feature. She talked about her situation where she was not sure if she was having a miscarriage or not, and she was in the dark for days until she was able to talk to her doctor. She thinks having a *Physical screener* would have helped her know if she passed her miscarriage successfully. She also mentioned, she was asked from her family doctors about her bleeding, pain, etc. Having a *Daily log* section would have helped monitor her symptoms and report them more accurately to the physician.

Participant C believes family and friends may not search for the information by themselves. However, inviting them creates greater chance that they would try the application and have access to important information. She also appreciated the *Safe space* section more than the other sections. She talked about the importance of reading the stories of other women who have gone through a similar experience while being able to share her story as well.

After my miscarriage the thing that helped me a lot was my friends telling me that this happens to their friends and family. They gave me the example of a healthy pregnancy after that. What was really hard for me was I didn't know that this is so common. So as much as I read about what this happens and people told me that this is common in their family and friends that helped me. So, I really like reading people's stories.—Participant C

#### 4.4.5.2 Quantitative Analysis

The participants evaluated the effectiveness, efficiency, and user satisfaction of *Miscarriage Corner* by answering SEQ and SUS questionnaires.

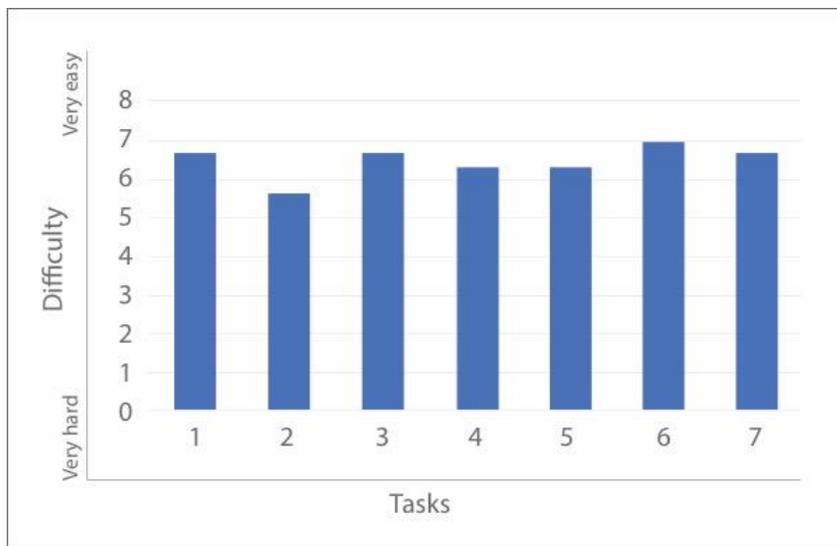
##### a. Effectiveness

The result shows 100% tasks were completed without reporting any difficulty while completing the tasks.

##### b. Efficiency

The SEQ results also show that the application is user-friendly and convenient.

**Figure 50** shows the level of task difficulty per task.



*Figure 50: The SEQ ratings for all participants, per task: from 1=Very difficult to 7=Very easy*

The following chart was designed by Jeff Sauro in regards to using SEQ to make an estimate about the task completion time and rate (MeasuringU: Using Task Ease (SEQ) to Predict Completion Rates and Times, 2018).

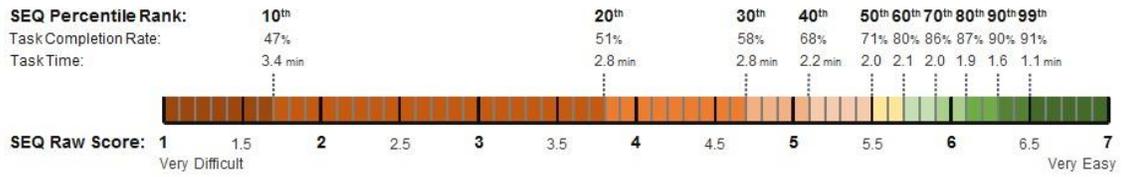


Figure 51: SEQ Percentile rank

**c. Satisfaction**

The average SUS score for *Miscarriage Corner* was 90.3, showing a high satisfaction degree among the participants. 80.3 is equivalent to an A. Any number higher than 80.3 shows that people like the application and would recommend them to others.

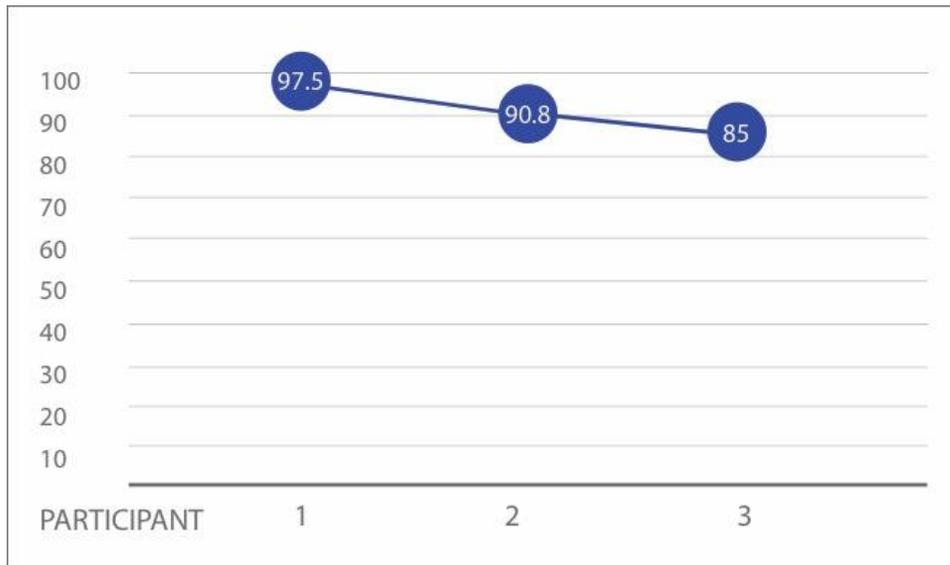


Figure 52: The SUS ratings for all participants

#### 4.5 Summary

The design opportunities were extracted from the interviews, co-design session with experts and analysis of existing miscarriage applications. Based on the findings a prototype for a mobile application *Miscarriage Corner* was created that aims to support immigrant women physically and emotionally after their miscarriage experience. A user-centred design (UCD) approach was employed to make sure the user is always at the centre of the design process. To validate and confirm the proposed design solution, user testing sessions were conducted with immigrant women in Canada. The final prototype was edited and iterated based on the data analysis from the user testing sessions.

## 5. Conclusion

In this chapter, I summarize my findings, address the limitations and challenges of the study, and conclude with possible future recommendations for this research.

### 5.1 Research Findings

The following are the main findings of this study:

#### a. Women do not Receive Enough Care after a Miscarriage

Several studies show women do not receive enough care after experiencing a miscarriage (See Chapter 2: Literature Review). Family and friends are often not aware that a miscarriage is taking place, since 80% of miscarriages happen within the first trimester and before announcing the pregnancy. (Petts, 2018). In the case where family and friends know about the miscarriage, they are still not a good source of support, according to what studies show. Family and friends may minimize the significance of the experience or act as if nothing happened (Hiefner, 2020; Layne, 1997). They sometimes expect women to just move on and go to another pregnancy, while not giving the time and opportunity to grieve. Women may also hesitate to share their feelings with their family and friends because they do not want to upset them. Immigrant women tend to have less family support from their extended family since they might be alone in Canada or their extended family may live in different cities, which makes the situation more challenging.

The Canadian healthcare system similar to many others, manages miscarriage in Emergency Departments (Freeman et al., 2020). As a result, healthcare providers play an important role in how the experience of a miscarriage is shaped since women have their first interactions with them (Heinifer, 2020). Despite the importance of this support, multiple studies show women do not

receive enough care from healthcare providers and often find their experience unpleasant. The problems include, lack of sympathy and compassion from the healthcare providers, lack of emotionally sensitive language and attitude, minimizing the loss of a miscarriage experience, rushed visits, lack of clarity on what women can expect next, etc. (Baird et al., 2018; Rowlands & Lee, 2010; Freeman et al., 2020).

Therapy is an essential resource that helps patients to deal with their mental wellness and trauma after a miscarriage. Despite its importance, it is not easy for women to have access to therapy. Unfortunately, the cost of therapy in Canada is high and it is not covered in most insurance plans. Since immigrant women tend to have a lower income compared to Canadian-born women, the chance of receiving therapy is much lower for them. In addition, women who have children at home, need additional support from other people to take care of their children to be able to attend the therapy sessions. Immigrant women with less family support in Canada have a harder time finding the support they need to attend the sessions.

#### **b. Immigrant Women Experience Miscarriage Differently**

Communication and cultural differences are two major issues immigrant women experience. Women's cultural discourse and personal circumstance might influence not only their understanding of miscarriage but also what care they expect to receive after a miscarriage (Freeman et al., 2020). It is important to consider the different cultural practices and how women think about loss or grief from different perspectives. Some cultures may find it hard to talk about sexual health. In these cultures, birth and positive topics are celebrated but when it comes to miscarriage and loss, they prefer to manage them in silence. As a result, they may not be open to accept help from family, friends nor a healthcare system.

The same applies to the willingness to accept therapy since miscarriage is still taboo in many cultures.

New immigrants' self-advocacy in navigating the Canadian healthcare system is hampered by low confidence and poor language proficiency, which makes it challenging for them to express their needs (Ghahari et al., 2020). They may not feel empowered to advocate for their own health, due to language barriers. Sometimes they may take doctor's words at value and not question them if they do not understand the instruction or procedure. It may cause a delay in recovery and limit their connection with healthcare. Since most resources are provided in English and French, lack of fluency in both these languages makes it hard for immigrant women to access reliable resources. They may also find it challenging to participate in grief counselling groups and express their feelings. The same applies to their connection and meetings with therapists.

**c. Normalizing the Experience Could Help Women Deal Better with their Miscarriage**

All interviewees believe the first step in helping women who have had a miscarriage is by normalizing the miscarriage experience. Since the topic of miscarriage has not been taught in birth classes, when parents experience a miscarriage, they have little to no information about them and how often miscarriages happen. Furthermore, family and friends often do not share their experience of a miscarriage and women who have had a miscarriage for the first time, do not know how common they are. Raising awareness about what percentage of women experience a miscarriage, and why and when it happens may help women feel less lonely in their journey. In addition, it is important to highlight that women are not causing their miscarriages, so they should not blame themselves for what happened. While normalizing the experience, it is

important to make sure we are not minimize it. Minimizing the experience can cause women to feel less inclined to ask for help since they do not want to take energy and time of friends, family and professionals assuming it is a more minor issue.

**d. Women Need Physical and Emotional Support after a Miscarriage**

All interviewees hold the view that providing physical support for women has the potential to help them in their recovery after a miscarriage. When women receive the information at the right time, they experience less stress, and as a result less trauma. Providing good physical support for women is an important first step in gaining their trust to further provide the emotional support they may need. Women may have several questions regarding what is normal, what is not normal and what to expect from their body after miscarriage. Answering these questions and offering relevant resources for women to inform themselves about miscarriages, may help them feel more empowered and in control of the situation.

Interviewees also believe women need emotional support after a miscarriage to better manage their mental health. The previous grief model that encouraged patients to stop thinking and talking about their issues is now outdated. The new model encourages patients to continue a bond with their passed away babies and acknowledge their loss. Anxiety, guilt and lack of self-care support are the most common emotional issues women have after a miscarriage. Women may punish themselves by not eating and sleeping well because they blame their bodies for losing their babies. Providing emotional resources and mental health support may help women overcome those feelings and start the healing process.

**e. Providing Resources Help Women in their Healing Journey**

The rate of recovery is very high when women are connected to good support systems and appropriate resources. When women are grieving, they may find it hard to find the resources and verify if they are credible. Providing women with valid resources can help educate them by providing the correct information about miscarriage and understanding what they should expect physically and emotionally, where to seek support, etc. Women should be provided with holistic and reliable resources that address all the psychological and physical aspects of a miscarriage. It is important to provide resources based on the geographical locations of where they are located. The resources also should be customized for women from different cultures and languages to make them more immigrant-friendly. Simplicity in the language and navigation of the information provided is crucial to be accessible for people with different levels of English proficiency.

**f. There is True Value in Women Supporting Women**

Women supporting women has always been cross-culturally accepted. Even if a woman has never had a miscarriage, they can still empathize, support and provide comfort to women who experience a miscarriage. In addition, it is beneficial to know about other women's experience with miscarriages. Knowing that they are not the only person who is experiencing this difficult experience makes it easier for them to accept what they are going through. Seeing other women who have experienced the same can help them not feel alone and isolated. Peer-to-peer support should include women from different cultures. It helps immigrant women to feel more connected and less excluded from the provided support and offers them a credible resource to ask the questions about miscarriage that they may have.

**g. Partners Should not be Excluded from the Support**

Interviewees believe partners should not be excluded from the miscarriage support because some partners may grieve to the same level as the birthing person while some may not. Partners should be provided with two different types of support; 1) offering resources and support as a person experiencing a traumatic event and 2) advice on how they can provide support to their partners experiencing a miscarriage. Training partners with basic mental health aid support can make them a great source of support for women. In some cultures, partners may play an important role in decision making of the family. Their decisions may dictate what a woman should do and how they should act after a miscarriage. In some cultures, men blame women for a miscarriage and even may divorce their spouse. Providing resources for men to inform themselves might help raise their awareness about miscarriages and help them better understand the reasons behind a miscarriage.

**h. What to Consider While Designing for Health Apps**

Interviewees believe designing for health is different from non-health in many ways. While designing for health the product needs to be designed in a way that the user feels empowered and in control of everything. When people are dealing with health-related issues they are not in control of the situation. Women may feel disempowered and not in control of their bodies, so it is crucial to make sure the design does not add the stress of uncertainty in their experience. In addition, the users may be sick while using the health-related platform, which may affect their cognitive ability. As a result, they might process the information differently. The design should use the simplest, yet still appropriate, approach as possible. The designer should make sure everything should be consistent with what women are used to in their daily life with very low level of learnability.

Using simple language and avoiding medical jargon is highly recommended while designing for health-related applications. The user should not be forced to check the dictionary while seeking information. Using simple words help users feel more in control and less scared of what they are going through. It is important to add minimum features to an mHealth application to make sure it is easy to use and do not overwhelm the users. All features should meet the needs of the users, otherwise they should be removed from the application. This approach prevents making the user feel overwhelmed, especially when they are sick and dealing with physical or emotional uncertainties.

### **i. Designing for Specific Groups**

Interviewees believe designing for women is different than designing for other genders. Historically much of the world has been both designed by and built for men, and we can see these decisions throughout society. In North America, we see a dominant approach that presents an idealized woman and forces women to try and achieve this ideal. It is important for the designed mHealth app to break this tradition and lessen the pressure the media puts on women. The design, both in visuals and context, has the ability to promote a more inclusive approach and help women feel more understood and empowered.

In addition, it is important to consider the different women with different perspectives. Some women may be more thorough and detail-oriented while some may be more spontaneous and disorganized. Different groups may need different levels of information, with or without the need to know the process. The design should recognize all these differences and meet the varied needs. Gaining women's trust is considered to be hard, especially while designing for more educated cohorts. The designer should provide all the relevant details and create an atmosphere that women can trust. Creating trust is especially important while

designing for health apps. Women are also community builders; they are good at creating relationships. Designing an application can be an opportunity to provide women with the ability to connect with other women experiencing a similar situation. Creating a platform where women can share their thoughts and learn from one another is a great asset while designing for women.

Interviewees believe the language we use for immigrant populations should be simple and easy to understand, for them to be able to make an informed decision about their health. As immigrants come from different health backgrounds, they may not fully understand the ecosystem and how healthcare works in Canada. Providing information for immigrants should be done from very basic to advanced, without making any assumptions that they may have existing knowledge about healthcare in Canada. This approach will help patients feel more secure about what they know, and help reduce their anxiety of feeling like they do not know enough. In addition, while designing for immigrants, it is important to use culturally appropriate visuals (colour, imagery, etc.). Having user testing sessions with people from different cultures helps in recognizing biases that exist and with identifying any culturally inappropriate visuals. Use of imagery is also recommended while designing for people whose first language is not English. This will help the end-user find it easier to understand the application, despite their possible lower level of proficiency in English.

## **5.2 Limitations**

While conducting this research, I encountered certain limitations and challenges. The following limitations of the study are discussed:

### **a. Including Women Who Have Had a Miscarriage in Research**

## Chapter 5: Conclusion

The Design Thinking framework has been employed to conduct this study. The framework has four stages; define, discover, create and evaluate. As part of user-centred design approach, the user should be involved in all stages of the design. In this study, the end-users of the application are immigrant women who have experienced a miscarriage and seek support after their experience. Due to the limitations of my ethics application, I was not able to conduct interviews with women who have experienced a miscarriage or have them as part of the co-design session. I had to rely on the information provided by experts in the field of obstetrics/gynecology, psychology and grief counselling. They provided valuable insight about miscarriage and shared knowledge and experience to help me have a good understanding of these women's needs. However, I still believe there is a huge benefit in conducting research with real users and not the stakeholders.

### b. User Testing

Faulkner (2003) expresses that a minimum of five participants can help researchers find 99% of the problems in a user testing activity. In this research, the goal was to do user testing with five immigrant women who have had a miscarriage in the past five years, are fluent in English and are from 18 to 44 years of age. Due to limitations of recruiting participants, I had to rely on my contact person in ParentCare Society of Edmonton and Vital Global. Unfortunately, I was only able to recruit three participants who have experienced a miscarriage in the past five years, instead of the five participants I had hoped for. All participants were well-educated and fluent in English and have lived in Canada for numerous years. I strongly believe the experience of using the application is different for newcomers and immigrants with a lower level of education compared to the participants of this user testing study. As a result, the participants in this study do not completely express the complete range of end-users of this application.

**c. Providing Content**

Testing content with the user is an important part of user testing, especially while designing a health-related informative platform. Card sorting is a great activity to find how information should be categorized and presented to the users. Due to the limitations of the study, I was not able to provide all the content the user will be provided. In addition, the framework for creating the *Emotional Screener* was given to me by the psychologist I interviewed a few days after finishing the user testing sessions with women. As a result, I was not able to test the *Emotional Screener* with the participants. In future research I would be sure to further test the *Emotional Screener* with participants.

**d. COVID-19 Pandemic**

Due to the COVID-19 pandemic, both co-design session with experts and user testing with women were conducted online through Zoom. During the co-design session, participants were asked to use Jamboard to take part in different activities such as brainstorming and voting. One of the participants did not have access to Gmail and Jamboard. She was not able to participate by herself and relied on me to help her with the process. She was confused in some activities and could not participate in a few sections. I believe the data provided by this participant would be more thorough if she could have access to activities by herself. In addition, the activity missed the energy, participation and interaction participants usually have in an in-person session. Having all participants in a room would make them feel more connected and possibly help with generating better ideas.

Due to the limitations of the study, I was not able to conduct in-person testing. In-person sessions let the designer read the body language and subtle signals like sighs, genuine expressions or struggles the user may experience. In addition,

participants may get more distracted during online user testing, compared to an in-person setting. In user testing sessions, participants were asked to share their screen for the researcher to observe how the user navigates through the application. The user testing of the mobile application prototype was conducted on desktop due to the online setting, which would be different from a genuine interaction with a mobile application prototype on a mobile. This may affect the testing for size of the icons, legibility of the text etc.

### 5.3 Future Recommendations

#### a. Conducting Research with Immigrants

As mentioned earlier, it is essential to have end-users involved in all stages of the study while designing for them. The barriers immigrants experience in the first years of entering a new country are more intense, in comparison to people that have lived in a country for years. Cultural differences may be a less serious issue if the person immigrated during their childhood. In addition, they may become more and more fluent in English living in Canada. The level of education could also have an impact on the experience of miscarriage for different women. Therefore, further studies should be conducted with a more holistic group of immigrants including newcomers and women with lower education levels to make sure all possible users are included in the study. In addition, conducting the research with a larger sample group of users can help the researcher better understand the needs of different groups of people.

#### b. Pregnancy after a Miscarriage

Based on the literature review and interviews with experts, pregnancy after a miscarriage is an important issue to address and women need to seek physical and mental support before planning a new pregnancy. Pregnancy after a miscarriage is highly correlated with postpartum and peripartum anxiety and depression. It is

important to support women emotionally and answer all their possible questions, while they are pregnant. Women might be worried about the chance of having a recurrent pregnancy loss after their previous loss. They may also struggle controlling their anxiety and stress during the pregnancy. Further studies are needed to be conducted for women experiencing a pregnancy after miscarriage to include the most appropriate and relevant resources for their needs in the application.

### c. Miscarriage During COVID-19 Pandemic

Since the start of COVID-19 pandemic, many hospitals limited the number of people in the emergency room. As stated by one of the interviewees, women experiencing a miscarriage are often not allowed to have their partners with them during their examination. Sometimes they have to stay for long hours by themselves without knowing if they have lost their baby or not. This situation can be an extremely traumatic experience for women, which could be worse for immigrant women who struggle with language barriers.

## 5.4 Summary

Going through a miscarriage can be a painful and challenging experience that can bring up feelings of resentment, anger, self-hate, etc. This study presents the potential for technology—through an mHealth application—in providing physical and emotional support for immigrant women who have experienced a miscarriage. Creating a platform that can offer women a community of other women who have experienced a similar situation can be both supportive and empowering. This study illustrates the process of designing a prototype for a mobile health application entitled *Miscarriage Corner* that aims to provide customized support for immigrant women. The application aims to design an easy to navigate informative platform to

## *Chapter 5: Conclusion*

create a satisfying user experience for women with different needs through their miscarriage experience.

This research has investigated the physical and emotional needs, frustrations and challenges that immigrant women experience during and after their miscarriage. It highlights the lack of support women experience in different situations and the impact they have on their mental health. The project explores the possible solutions and design recommendations for creating a more holistic and accessible support system for immigrant women experiencing a miscarriage and empowers them with knowledge and information they may need for their healing. Further research and testing on possible solutions for women experiencing a miscarriage is crucial to create a better experience through this vulnerable time, which will help them through their healing process.

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## **7. Appendices**

### **7.1 Ethics Application**

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**Pro00109089**

1.1 Study Identification

Status: Approved

### 1.1 Study Identification

All questions marked by a *red asterisk* \* are required fields. However, because the mandatory fields have been kept to a minimum, answering only the required fields may not be sufficient for the REB to review your application.

Please answer all relevant questions that will reasonably help to describe your study or proposed research.

- 1.0 \* **Short Study Title** (restricted to 250 characters):  
Development of a digital information platform to enhance usability and accessibility for immigrant women who have experienced a miscarriage.
- 2.0 \* **Complete Study Title** (can be exactly the same as short title):  
Development of a digital information platform to enhance usability and accessibility for immigrant women who have experienced a miscarriage.
- 3.0 \* **Select the appropriate Research Ethics Board** (Detailed descriptions are available at [here](#)):  
Research Ethics Board 1
- 4.0 \* **Is the proposed research:**  
Unfunded
- 5.0 \* **Name of local Principal Investigator:**  
Mehmoush Zeidabadi
- 6.0 \* **Type of research/study:**  
Graduate Student
- 7.0 **Investigator's Supervisor**(required for applications from undergraduate students, graduate students, post-doctoral fellows and medical residents to REBs 1 & 2. HREB does not accept applications from student PIs):  
Gillian Harvey
- 8.0 **Study Coordinators or Research Assistants:** People listed here can edit this application and will receive all email notifications for the study:  

Name	Employer
There are no items to display	
- 9.0 **Co-Investigators:** People listed here can edit this application and will receive email notifications (Co-investigators who do not wish to receive email, should be added to the study team below instead of here). If your searched name does not come up when you type it in the box, the user does not have the Principal Investigator role in the online system. Click the following link for instructions on how to [Request an Additional Role](#).

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**Name** **Employer**

There are no items to display

**10.0 Primary Admin Contact** *(a member of study team):*

**11.0 Study Team:** *(co-investigators, supervising team, and other study team members) - People listed here cannot view or edit this application and do not receive email notifications.*

Last Name	First Name	Organization	Role/Area of Responsibility	Phone	Email
There are no items to display					

**ID:** Pro00109089 **Pro00109089** 1.4 Conflict of Interest

**Status:** Approved

**1.4 Conflict of Interest**

**1.0** \* Are any of the investigators or their immediate family receiving any personal remuneration (including investigator payments and recruitment incentives but excluding trainee remuneration or graduate student stipends) from the funding of this study that is not accounted for in the study budget?

Yes  No

**2.0** \* Do any of investigators or their immediate family have any proprietary interests in the product under study or the outcome of the research including patents, trademarks, copyrights, and licensing agreements?

Yes  No

**3.0** \* Is there any compensation for this study that is affected by the study outcome?

Yes  No

**4.0** \* Do any of the investigators or their immediate family have equity interest in the sponsoring company? (This does not include Mutual Funds)

Yes  No

**5.0** \* Do any of the investigators or their immediate family receive payments of other sorts, from this sponsor (i.e. grants, compensation in the form of equipment or supplies, retainers for

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ongoing consultation and honoraria)?

Yes  No

6.0 \* Are any of the investigators or their immediate family, members of the sponsor's Board of Directors, Scientific Advisory Panel or comparable body?

Yes  No

7.0 \* Do you have any other relationship, financial or non-financial, that, if not disclosed, could be construed as a conflict of interest?

Yes  No

Please explain if the answer to any of the above questions is Yes:

**Important**

If you answered YES to any of the questions above, you may be asked for more information.

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1.5 Research Locations and Other Approvals

Status: Approved

**1.5 Research Locations and Other Approvals**

1.0 \* List the locations of the proposed research, including recruitment activities. Provide name of institution, facility or organization, town, or province as applicable  
Internet to record interviews, co-design sessions and usability testing sessions (On Zoom).

2.0 \* Indicate if the study will use or access facilities, programmes, resources, staff, students, specimens, patients or their records, at any of the sites affiliated with the following (select all that apply):  
Not applicable

List all health care research sites/locations:

3.0 Multi-Institution Review

\* 3.1 Has this study already received approval from another REB?  
 Yes  No

4.0 If this application is closely linked to research previously approved by one of the University of Alberta REBs or has already received ethics approval from an external ethics review board(s), provide the study number, REB name or other identifying information. Attach any external REB application and approval letter in the Documentation Section – Other Documents.

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2.1 Study Objectives and Design

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Status: Approved

## 2.1 Study Objectives and Design

### 1.0 \* Provide a lay summary of your proposed research which would be understandable to general public

The purpose of this study is to uncover the ways that technology and design can promote dissemination of information for immigrant women who have experienced a miscarriage.

### 2.0 \* Provide a full description of your research proposal outlining the following:

- Purpose
- Hypothesis
- Justification
- Objectives
- Research Method/Procedures
- Plan for Data Analysis

#### Purpose/ Hypothesis/ Justification

The area of digital health for women—popularized as Femtech—is an underutilized healthcare

technology. Femtech refers to technologies, software and digital solutions that assist women to

manage their health and well-being. While there are some attempts to improve women's

health and well-being using technology, Femtech still remains a significantly underdeveloped

part of healthcare. A practical digital solution that provides a platform for women to receive the

information they need after experiencing a miscarriage, as well as being in touch and sharing

their experience with their support group, could help immigrant women cope with the grief and

going back to a sense of normalcy.

**Discovering and better understanding the needs of health information for immigrant women after a miscarriage: Development of a digital health solution** focuses on exploring the role of usability and accessibility in an online or digital app experience. The purpose of the research is to collect data from experts who provide information to women after they have experienced a miscarriage. I will use the data to design an online platform that provide information to these women.

The study has two main objectives to:

1. identify the current process of providing information about post-procedure care, such as becoming pregnant after a miscarriage, menstruation cycles after a miscarriage, risk of having another

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miscarriage, and to analyze the information to understand the user's perception of the experience.

2. to design a digital health solution / digital information platform for users to enhance relevant information.

The qualitative evidence from some studies shows that there is a lack of medical care provided to the patients during and after a miscarriage (Rowland and Lee, 2010). In most countries around the world, including Canada, the emergency departments are the first place for patients seeking healthcare for pregnancy loss symptoms. In addition to that, primary healthcare providers such as physicians, nurse practitioners and midwives, including an increasing number of Early Pregnancy Assessment Units (EPAUs), provide care to individuals. Despite the importance of patient's interaction with healthcare after a miscarriage, many women reported their experience with healthcare providers as rushed or inadequate in meeting their information and emotional needs (Freeman, Neiterman and Varathasundaram, 2019). A recent survey of 300 French women, who experienced a pregnancy loss, showed that 78 per cent of the women weren't given adequate information about the causes of miscarriage, and 82 per cent subsequently worried about future pregnancies (Klein, 2020).

Immigrant populations such as Asian, Middle-eastern, European and African that include 20 per

cent of Canadian women access health services differently. In this study, immigrants refer to

anyone born outside Canada and has settled permanently in this country. Several studies and reviews highlight that in Canada, the experience of an immigrant seeking healthcare is filled with barriers related to immigration experience, including cultural differences, language barriers, lack of information about how to access or navigate services, discrimination, inadequate social support and differences in expectations (Kalich, Heinemann and Ghahari, 2016).

#### **Research Method/ Procedures**

- Interviews with psychologists to find out 1) which digital solutions for dealing with grief in a digital platform are recommended to patients currently, and 2) what appropriate grief resources and references are.
- Interviews with obstetricians and gynaecologists to collect data about the physical and emotional information support resources that are needed after a miscarriage.
- Interviews with professionals in the field of user experience design and human-centred design to learn how to use human interaction to improve the user's experience.
- Interviews with social workers who work with women who have had miscarriages to understand what women need after a miscarriage and discuss what information would be helpful in a digital health platform.
- Co-design sessions with experts to create the first draft wire-frames of the digital solution.
- User testing with immigrant women to evaluate the developed digital health solution. The results would be employed to redesign the application and improve the experience of users.

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**Data analysis**

**Interviews**

- I will use an Excel spreadsheet to organize the interview data for analysis.
- Field notes: During the interviews, co-design and usability testing sessions, I will take field notes to identify the problems and concepts better.
- Coding: I will transcribe all the interviews to identify patterns of themes in the interview data. Then I will assign preliminary codes to the relevant words, phrases, sentences, or sections in order to describe the content. Then I will create categories and subcategories by grouping the codes.
- Identifying patterns: I will search for patterns or themes in the codes across the different interviews. The frequency as well as how important a certain code is being considered at the stage of identifying patterns in the data.
- Summarizing the data would be the last step of analyzing the data.

**Usability testing**

To examine the quality of how well tasks are fulfilled by the users (usability testing), I will use ISO 9241-11 framework. ISO 9241-11 provides a framework for understanding the concept of usability. There are three components in this framework: System Effectiveness to examine the users' ability to complete the given tasks, System Efficiency to examine the required user resources to complete the tasks, and System Satisfaction to record the users' opinions and feedback (Constantinescu et al., 2019)

- 3.0 Describe procedures, treatment, or activities that are above or in addition to standard practices in this study area (eg. extra medical or health-related procedures, curriculum enhancements, extra follow-up, etc):**  
NA
- 4.0 If the proposed research is above minimal risk and is not funded via a competitive peer review grant or industry-sponsored clinical trial, the REB will require evidence of scientific review. Provide information about the review process and its results if appropriate.**  
NA
- 5.0 For clinical trials, describe any sub-studies associated with this Protocol.**  
NA

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**Status:** Approved

2.2 Research Methods and Procedures

**2.2 Research Methods and Procedures**

*Some research methods prompt specific ethical issues. The methods listed below have additional questions associated with them in this application. If your research does not involve any of the methods listed below, ensure that your proposed research is adequately described in Section 2.1: Study Objectives and Design or attach documents in the Documentation Section if necessary.*

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- 1.0 \* This study will involve the following (select all that apply)**  
Internet-based Interaction with Participants (excluding internet surveys or data collection over internet without human interaction)  
Interviews and/or Focus Groups  
Materials created by participants (eg. artwork, writing samples, photo, voice, etc.)  
Participant Observation

*NOTE 1: Select this ONLY if your application SOLELY involves a review of paper charts/electronic health records/administrative health data to answer the research question. If you are enrolling people into a study and need to collect data from their health records in addition to other interventions, then you SHOULD NOT select this box.*

*NOTE 2: Select this option if this research ONLY involves analysis of blood/tissue/specimens originally collected for another purpose but now being used to answer your research question. If you are enrolling people into the study to prospectively collect specimens to analyze you SHOULD NOT select this box.*

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Status: Approved

2.4 Internet-based Interaction with Human Participants

**2.4 Internet-based Interaction with Human Participants**

- 1.0 Internet-based Research**
- 1.1 Will your interaction with participants occur in private internet spaces (eg. members only chat rooms, social networking sites, email discussions, etc)?**  
 Yes  No
- 1.2 Will these interactions occur in public space(s) where you will post questions initiating and/or maintaining interaction with participants?**  
 Yes  No
- 2.0 Describe how permission to use the site(s) will be obtained, if applicable:**  
I will conduct interviews, co-design sessions and user testing through Zoom. Zoom meetings will be password protected.
- 3.0 If you do not plan to identify yourself and your position as a researcher to the participants, from the onset of the research study, explain why you are not doing so, at what point you will disclose that you are a researcher, provide details of debriefing procedures, if any, and if participants will be given a way to opt out, if applicable:**
- 4.0 \* How will you protect the privacy and confidentiality of participants who may be identified by email addresses, IP addresses, and other identifying information that may be captured by the system during**

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**your interactions with these participants?**

The principal investigator is the only person who has access to the email addresses, and it will not be shared with anyone else. Right after finishing the study, personal identifiers will be destroyed.

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2.5 Interview and/or Focus Groups

Status: Approved

**2.5 Interview and/or Focus Groups**

**1.0 Will you conduct interviews, focus groups, or both? Provide detail.**

I will conduct interviews.

Interviews will be conducted to receive qualitative data from experts (obstetrician and gynaecologists, psychologists, User experience designers and social workers).

Mehrnoush Zeidabadi, the principal investigator, will conduct the interviews.

**2.0 How will participation take place (e.g. in-person, via phone, email, Skype)?**

Participants' participation will take place online (on Zoom). All meetings will be password protected.

**3.0 How will the data be collected (e.g. audio recording, video recording, field notes)?**

Data for Interviews will be collected through audio recording. Online interviews will be held on Zoom and transcribed with Otter.ai. Recordings will be made locally to the researcher's computer. All meetings will be password protected.

Data for co-design sessions and user testing sessions will be collected through video recording online on Zoom and transcribed with Otter.ai. Recordings will be made locally to the researcher's computer. All meetings will be password protected.

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2.6 Material Created by Participants

Status: Approved

**2.6 Material Created by Participants**

**1.0 Provide a summary of the materials created by participants that will be included in this research project:**

Experts will participate in one co-design session to create the wireframes of the mobile application. A co-design session is a process of creating with stakeholders or customers to ensure that the result meets their needs and is suitable. In this session, experts from obstetrics and gynaecology, psychology and community social work will receive an analogue or digital wire-framing kit. Wire-framing kit has different components of a website or application such as texts, pictures, action buttons, etcetera. Experts will use these components to prototype a low fidelity digital solution with features they believe immigrant women who have experienced a miscarriage need.

**2.0 Who will have access to this data?**

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The principal investigator

**3.0 When publicly reporting data or disseminating results of your study (eg. presentation, reports, articles, books, curriculum material, performances, etc) that include the materials created by participants, what steps will you take to protect those who may be represented or identified - both participants and non-participants?**

The participants' names will not be identified by name in public presentations and written articles, except if they choose to be acknowledged. They will be asked if they want to get credit for what they created on the consent form.

**4.0 What opportunities are provided to participants to choose to be identified as the author/creator of the materials created in situations where it makes sense to do so?**

Participants (experts) will have the option to receive credit for the wireframes they will create. They will also have the option to be acknowledged for their interviews. This option will be provided in the consent form to participants prior to having the interview or co-design session.

**5.0 If necessary, what arrangements will you make to return original materials to participants?**

The material will be created as a part of the project.

Because of the online nature of the project, participants will create the work at their own place, and as a result, they will have the original work. They will send me a copy of the work they created after the co-design session.

**6.0 Will you be using audio/video recording equipment and/or other capture of sound or images for the study?**

Yes  No

**If YES, provide details:**

Participants will be observed online while conducting the co-design session and user testing, and their session will be video recorded. It will help me understand the reasons behind the decisions participants make in the co-design session and what are their thoughts and feelings during user the testing session.

Interviews will be audio-recorded and transcribed with Utter.ai. I need the recordings to be able to analyze the data later.

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2.7 Participant Observation

Status: Approved

### 2.7 Participant Observation

**1.0 Who will the observer be?**

The observer will be principal investigator, Mehrnoush Zeidabadi.

**2.0 Who is being observed?**

Experts in the field of obstetrics/gynaecology, psychology and community social work will be observed while creating wireframes. I will have three co-design sessions, one session with one expert from each field.

Immigrant women of reproductive ages (18- 44) who have experienced pregnancy loss in the previous five years will be observed while

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participating in the user testing session. I will have one user testing session with each participant (A total of five participants).

**3.0 Why are they being observed?**

Experts will be observed to see how they create wireframes in the co-design session. Wireframing is a two-dimensional skeletal outline of a webpage or app that provides a clear overview of the page structure, layout, information architecture, user flow, functionality, and intended behaviours. Creating wireframes will help me to understand the best way to organize and display the information.

Observing experts' interaction and the decision-making process while creating the wireframes provides more information for me to understand the intention behind each decision.

Immigrant women who have experienced a miscarriage in the previous five years will be observed while participating in the user testing session. They will be asked to think aloud while using the prototype of the mobile application. Observing participants help me to understand which parts of the application needs more refinements.

**4.0 When and where will participants be observed (i.e. during class, during their workday)?**

Participants will be observed online (on Zoom) while conducting the co-design session and user testing.

**5.0 Will others be present who are not being observed (i.e. non-participants)?**

Yes  No

**6.0 What data will be collected?**

Video and/or audio recordings  
Field notes

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3.1 Risk Assessment

Status: Approved

**3.1 Risk Assessment**

**1.0 \* Provide your assessment of the risks that may be associated with this research:**

Minimal Risk - research in which the probability and magnitude of possible harms implied by participation is no greater than those encountered by participants in those aspects of their everyday life that relate to the research (TCPS2)

**2.0 \* Select all that might apply:**

Description of Possible Physical Risks and Discomforts

No Participants might feel physical fatigue, e.g. sleep deprivation

No Participants might feel physical stress, e.g. cardiovascular stress tests

No Participants might sustain injury, infection, and intervention side-effects or complications

No The physical risks will be greater than those encountered by the participants in everyday life

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Possible Psychological, Emotional, Social and Other Risks and Discomforts

No Participants might feel psychologically or emotionally stressed, demeaned, embarrassed, worried, anxious, scared or distressed, e.g. description of painful or traumatic events

Possibly Participants might feel psychological or mental fatigue, e.g intense concentration required

No Participants might experience cultural or social risk, e.g. loss of privacy or status or damage to reputation

No Participants might be exposed to economic or legal risk, for instance non-anonymized workplace surveys

No The risks will be greater than those encountered by the participants in everyday life

**3.0 \* Provide details of all the risks and discomforts associated with the research for which you indicated YES or POSSIBLY above.**  
Participants may feel mentally fatigued after giving feedback in a user testing session.

**4.0 \* Describe how you will manage and minimize risks and discomforts, as well as mitigate harm:**  
Immigrant women who have experienced a miscarriage will only be a part of user testing session.

I will carefully describe the research study to the participants while outlining the risk and benefits of being involved and how the data will be used and disseminated.

They will be notified and reminded at the beginning of each session that they can withdraw at any time they want without consequences. They also can turn their cameras off anytime they want.

**5.0 Is there a possibility that your research procedures will lead to unexpected findings, adverse reactions, or similar results that may require follow-up (i.e. individuals disclose that they are upset or distressed during an interview/questionnaire, unanticipated findings on MRI, etc.)?**  
 Yes  No

**6.0 If you are using any tests in this study diagnostically, indicate the member(s) of the study team who will administer the measures/instruments:**

Test Name	Test Administrator	Organization	Administrator's Qualification
There are no items to display			

**7.0 If any research related procedures/tests could be interpreted diagnostically, will these be reported back to the participants and if so, how and by whom?**  
NA

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3.2 Benefits Analysis

Status: Approved

### 3.2 Benefits Analysis

- 1.0 \* Describe any potential benefits of the proposed research to the participants. If there are no benefits, state this explicitly:**  
Group 1: Women who have experienced a miscarriage  
Women will provide feedback on a digital platform and provide feedback on the designed application. The main benefit of these talks and activities will be to me as the researcher. There may be no direct personal benefits to this research.
- Group 2: Experts  
Experts will contribute to and providing information from their area of their expertise and interest with the aim of having a resource for experts to provide to their patients. The main benefit of this interview will be to me as the researcher. There may be no direct personal benefits to this research.
- 2.0 \* Describe the scientific and/or scholarly benefits of the proposed research:**  
The proposed research will contribute to the body of research that exists regarding how technology can help improve women's health and well-being. In this study, the perspective of immigrant women, based on their personal experience, will be collected. This data will help to design better digital health solutions for this group of people with specific needs.
- 3.0 If this research involves risk to participants explain how the benefits outweigh the risks.**  
The result of this research helps immigrant women who experience pregnancy loss to follow-up with their situations physically and emotionally. It is important that their experience and perspectives are taken into account while creating a solution for them.
- In this proposed research, the risk of mental fatigue and emotional stress from user testing. The application remains minimal and not more than what they experience in everyday activities. Given this, the potential benefits of the research outweigh the risks.

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4.1 Participant Information

Status: Approved

### 4.1 Participant Information

- 1.0 \* Will you be recruiting human participants (i.e. enrolling people into the study, sending people online surveys to complete)?**  
 Yes  No
- 1.1 Will participants be recruited or their data be collected from Alberta Health Services or Covenant Health or data custodian as defined in the Alberta Health Information Act?**  
 Yes  No

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4.2 Additional Participant Information

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Status: Approved

#### 4.2 Additional Participant Information

**1.0 Describe the participants that will be included in this study. Outline ALL participants (i.e. if you are enrolling healthy controls as well):**

Group 1: Experts

Experts connected to programs that work with women who have had a miscarriage, are practicing in their field and have an interest in the research.

The participants will be experts in the following fields:

Obstetrics and gynaecology

Psychology

User experience design

Community social work

Group 2: Women

The participants are the immigrant population in Canada of reproductive age (18-44) who have experienced pregnancy loss in the previous five years

**2.0 \* Describe and justify the inclusion criteria for participants (e.g. age range, health status, gender, etc.):**

Participants will be:

1. 18 years of age or older (in order to provide their own consent to participate)
2. fluent in English (in order to understand the instructions and study questionnaire)
3. working in their professional field of expertise with current accreditation

**3.0 Describe and justify the exclusion criteria for participants:**

1. younger than 18 years old
2. unable to fluently speak or read the English language
3. not working in their field of professional expertise

**4.0 Participants**

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**4.1 How many participants do you hope to recruit (including controls, if applicable?)**  
13

**4.2 Of these, how many are controls, if applicable?**

**4.3 If this is a multi-site study, how many participants do you anticipate will be enrolled in the entire study?**

**5.0 Justification for sample size:**  
The ideal number would be 5 participants for group 1 and 8 participants for group 2.

Group 1 (immigrant women who experienced pregnancy loss in the previous five year)  
I will conduct user testing sessions with five women.

Group 2 (Experts):  
I will conduct interviews with two obstetricians/gynaecologist, two psychologists, two user experience designers and two social worker. Also three experts (one obstetricians/gynaecologist, one psychologist and one social worker will also participate in a co-design session with me.

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Status: Approved

4.4 Recruitment of Participants (non-Health)

#### 4.4 Recruitment of Participants (non-Health)

##### 1.0 Recruitment

**1.1 How will you identify potential participants? Outline all of the means you will use to identify who may be eligible to be in the study (i.e. response to advertising such as flyers, posters, ads in newspapers, websites, email, list serves, community organization referrals, etc.)**

Recruiting obstetricians /gynaecologists

The first phase of the research builds on existing research and project relationships from medical experts from the organization Vitala Global Health that has indicated that they would like to be involved in this work. Vitala is an organization that works with and advocates for womens' health issues. Both of the directors of the Canadian organization will be emailed and asked if they or a medical professional within the organization or within their partnership groups would like to participate in the interviews. This will be done by email.

Recruiting social workers

For recruiting the social workers, I will send an initial letter of contact to the following organizations and contact people. The letter will ask the participants who are interested to contact the researcher directly. We will not share any contact information without consent.

ParentCare society of Edmonton- Ms. Patti Walker

H.E.A.R.T.S.- Ms. Chy Salter Roberts-

Angel Whispers- Ms. Lori-Ann Huot

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They may have an interview with me or refer me to one of the experts from their organizations.

#### Recruiting psychologists

For recruiting psychologists, I will ask the Psychologists Association of Alberta to insert a notice regarding the study into their communications with members. In addition, I will look at faculty of medicine, department of psychology of University of Alberta to find psychologists who have experience in working with women. I will send them a letter of initial contact with a brief description of my research and ask them if they are interested in being a part of this research.

#### Recruiting user experience designers

For recruiting user experience designers, I will send an initial letter of contact with a brief description of my research to the following organizations and ask them if they are interested in being a part of this research.

Interaction Design Association

UX Researchers Association

Usability Professionals Association

Hexagon UX

#### Recruiting Women for user testing sessions

The second phase relies on a contact person, Ms. Patti Walker, from the ParentCare Society of Edmonton to use an existing pool of resources within Edmonton. The Parent Care Support Society is a support group that helps parents who have suffered the loss of a baby through miscarriage and other medical factors. I will rely on Patti's relationship with women to provide information about the study to women in her support group. Women will be invited to contact the researchers directly and contact information will not be shared.

**1.2 Once you have identified a list of potentially eligible participants, indicate how the potential participants' names will be passed on to the researchers AND how will the potential participants be approached about the research.**

Participants names will be passed on to a representative from each of the interested groups; ParentCare Edmonton and Vitala.

For example, Ms. Patti Walker, from the PatentCare Society of Edmonton will gather interested participants' names. The names will then be sent to the Principal Investigator. The principal investigator will follow up with details about the user testing.

## 2.0 Pre-Existing Relationships

**2.1 Will potential participants be recruited through pre-existing relationships with researchers**(e.g. Will an instructor recruit students from his classes, or a physician recruit patients from her practice? Other examples may be employees, acquaintances, own children or family

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members, etc.)?  
 Yes  No

**3.0 Will your study involve any of the following?(select all that apply)**  
None of the above

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Status: Approved

**4.5 Informed Consent Determination**

**1.0 Describe who will provide informed consent for this study(i.e. the participant, parent of child participant, substitute decision maker, no one will give consent – requesting a waiver)**  
The participant will provide informed consent for this study. Since the interactions are online, oral consent will be obtained. A copy of the consent form will be provided to the participant in advance of the interview so that they have it in front of them while going through consent with me. The oral consent will be documented by video or audio recording and stored on the researcher's personal computer. The participants will be asked if they want to receive a copy of the oral consent form. A copy of the consent will be sent to them through email if they are willing to receive it.

**1.1 Waiver of Consent Requested**  
**If you are asking for a waiver of participant consent, please justify the waiver or alteration and explain how the study meets all of the criteria for the waiver. Refer to Article 3.7 of TCPS2 and provide justification for requesting a Waiver of Consent for ALL criteria (a-e)**  
For interviews conducted by Zoom, consent will be granted verbally. Consent forms will include the statement that by choosing to continue with the interview, one's consent is granted. In both of these cases, I will document their verbal consent on the consent form, including their name and date. Participants will be asked if they want to receive a copy of the consent form.

**1.2 Waiver of Consent in Individual Medical Emergency**  
**If you are asking for a waiver or alteration of participant consent in individual medical emergencies, please justify the waiver or alteration and explain how the study meets ALL of the criteria outlined in Article 3.8 of TCPS2 (a-f).**  
Signed consent form  
Verbal consent

**2.0 How will consent be obtained/documented? Select all that apply**  
Verbal consent

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**If you are not using a signed consent form, explain how the study information will be provided to the participant and how consent will be obtained/documented. Provide details for EACH of the options selected above:**

For interviews conducted by phone or video call, consent will be granted verbally. Consent forms will include the statement that by choosing to continue with the interview, one's consent is granted. In both of these cases, I will document their verbal consent on the consent form, including their name and date.

**3.0 Will every participant have the capacity to give fully informed consent on his/her own behalf?**

Yes  No

**4.0 What assistance will be provided to participants or those consenting on their behalf, who may require additional assistance? (e.g. non-English speakers, visually impaired, etc.)**

Non-english speakers are excluded from the study.

**5.0 \* If at any time a PARTICIPANT wishes to withdraw from the study or from certain parts of the study, describe when and how this can be done.**

Participants will have the option to withdraw their data within two weeks of the research activity was conducted.

If an expert participates in an interview but is not able to be a part of the co-design session, then they are able to do this without consequence.

**6.0 Describe the circumstances and limitations of DATA withdrawal from the study, including the last point at which participant DATA can be withdrawn (i.e. 2 weeks after transcription of interview notes)**

Data can be withdrawn up to two weeks after the research activity has been conducted. This will be outlined in the consent form and information sheet.

**7.0 Will this study involve any group(s) where non-participants are present? For example, classroom research might involve groups which include participants and non-participants.**

Yes  No

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5.1 Data Collection

Status: Approved

### 5.1 Data Collection

**1.0 \* Will the researcher or study team be able to identify any of the participants at any stage of the study?**

Yes  No

**2.0 Primary/raw data collected will be (check all that apply):**

**Indirectly identifying information** - the information can reasonably be expected to identify an individual through a combination of indirect identifiers (eg date of birth, place of residence, photo or unique personal characteristics, etc)

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- 3.0 If this study involves secondary use of data, list all original sources:**  
NA
- 4.0 In research where total anonymity and confidentiality is sought but cannot be guaranteed (eg. where participants talk in a group) how will confidentiality be achieved?**  
NA

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5.2 Data Identifiers

Status: Approved

### 5.2 Data Identifiers

- 1.0 \* Personal Identifiers:** will you be collecting - at any time during the study, including recruitment - any of the following (*check all that apply*):  
Surname and First Name  
Email Address  
Full Face Photograph or Other Recording  
Age at time of data collection  
Professional Certificate/License Number

- 2.0 Will you be collecting - at any time of the study, including recruitment of participants - any of the following (check all that apply):**  
There are no items to display

- 3.0 \* If you are collecting any of the above, provide a comprehensive rationale to explain why it is necessary to collect this information:**  
Group 1: Immigrant women who have experienced a miscarriage

Video recording:

Videos of participants will be recorded to show their interaction with the mobile app during the usability testing session. Recordings be made locally to the researcher's computer.

Age at the time of data collection:

The age of the participants will be important to provide the context in the research. It will also help to compare the data among different ages to understand the problem better.

Email addresses:

As for their emails, it will be good to have them in case I need to get in touch with them to arrange the meeting.

Surname and first name:

Surname and first name will be collected in case they want to delete their data from the study.

Experts in the fields of obstetrician/ gynaecology, psychology, user experience design and community social work:

Audio will be recorded during interviews.

Video will be recorded when they are creating wireframes in the co-design sessions.

Surname and first name:

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Surname and first name will be collected in case the participants want to be acknowledged for their work.

Email addresses:  
I need the email addresses for the initial contact with them.

Professional certificates/ license number:  
I need participants' professional background information to sort them into their area of expertise.

- 4.0 If identifying information will be removed at some point, when and how will this be done?**  
Identifying information (surname and first name and email addresses) will be deleted right after finishing the study, unless the participant wants to be acknowledged in the study.

Recordings, age of the participants and the certificate number of the experts will be kept.

- 5.0 \* Specify what identifiable information will be RETAINED once data collection is complete, and explain why retention is necessary. Include the retention of master lists that link participant identifiers with de-identified data:**  
All data collected will remain unidentified, assuring the anonymity of the participant's identity.  
For the expert interviews, the data will remain unidentified unless the expert wants to be acknowledged and cited in the study. They also will be asked if they would like their names to be mentioned in the study for the work they created in the co-design session.

Also, age will be attached to the work.

- 6.0 If applicable, describe your plans to link the data in this study with data associated with other studies (e.g within a data repository) or with data belonging to another organization:**  
NA

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5.3 Data Confidentiality and Privacy

Status: Approved

### 5.3 Data Confidentiality and Privacy

- 1.0 \* How will confidentiality of the data be maintained? Describe how the identity of participants will be protected both during and after research.**  
Protecting all people's anonymity and treating them with respect and courtesy is essential in the proposed research. The privacy of all people involved in this study will be considered at all times.  
All the data collected from the participants will be stored in the principal investigator's computer and hard drive. This data will not be stored on any cloud services or shared with anyone.  
  
All identifiable data will be stored separately on an external hard drive, password-protected encryption, and kept in a locked drawer.
- 2.0 How will the principal investigator ensure that all study personnel are aware of their responsibilities concerning participants' privacy and the confidentiality of their information?**  
The research has no study personnel.

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**3.0 External Data Access**

**\* 3.1 Will identifiable data be transferred or made available to persons or agencies outside the research team?**

Yes  No

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5.4 Data Storage, Retention, and Disposal

Status: Approved

**5.4 Data Storage, Retention, and Disposal**

**1.0 \* Describe how research data will be stored, e.g. digital files, hard copies, audio recordings, other. Specify the physical location and how it will be secured to protect confidentiality and privacy. (For example, study documents must be kept in a locked filing cabinet and computer files are encrypted, etc. Write N/A if not applicable to your research)**

Digital files (including notes and video recording) will be kept on an encrypted external hard drive. Hard copies will be locked in a filing cabinet in my personal residence. On my Mac, I will use Disk utility to encrypt project-related data.

**2.0 \* University policy requires that you keep your data for a minimum of 5 years following completion of the study but there is no limit on data retention. Specify any plans for future use of the data. If the data will become part of a data repository or if this study involves the creation of a research database or registry for future research use, please provide details. (Write N/A if not applicable to your research).**

There is no future use planned for the data.

**3.0 If you plan to destroy your data, describe when and how this will be done? Indicate your plans for the destruction of the identifiers at the earliest opportunity consistent with the conduct of the research and/or clinical needs:**

All personal identifiers (Surname and first name, email addresses) will be destroyed right after finishing the study.

All raw data will not be destroyed for five years. This would include all video and audio recordings, work created by participants and other collected data and materials.

After five years following the completion of my study, I will erase all digital data from the hard drive and shred all hard copies using a paper shredder in order to destroy the data.

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Documentation

Status: Approved

**Documentation**

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Add documents in this section according to the headers. Use Item 11.0 "Other Documents" for any material not specifically mentioned below.

Sample templates are available by clicking [HERE](#).

**1.0 Recruitment Materials:**

Document Name	Version Date	Description
 Disregard(0.05)	0.05	4/16/2021 1:05 PM

**2.0 Letter of Initial Contact:**

Document Name	Version Date	Description
 Initial letter of contact-community support group(0.04)	0.04	4/14/2021 10:43 PM
 Initial letter of contact-interview with experts(0.04)	0.04	4/14/2021 10:43 PM

**3.0 Informed Consent / Information Document(s):**

**3.1 What is the reading level of the Informed Consent Form(s):**

**3.2 Informed Consent Form(s)/Information Document(s):**

Document Name	Version Date	Description
 Consent form- co-design session with experts(0.03)	0.03	4/14/2021 10:43 PM
 Consent form- interview with experts(0.03)	0.03	4/14/2021 10:44 PM
 Consent form- user testing(0.03)	0.03	4/14/2021 10:44 PM
 Information letter- user testing(0.04)	0.04	4/14/2021 10:45 PM
 Information letter- interview and co-design session with experts(0.03)	0.03	4/14/2021 10:46 PM

**4.0 Assent Forms:**

Document Name	Version	Date	Description
There are no items to display			

**5.0 Questionnaires, Cover Letters, Surveys, Tests, Interview Scripts, etc.:**

Document Name	Version Date	Description
 Possible interview questions(0.02)	0.02	4/14/2021 10:47 PM

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**6.0 Protocol/Research Proposal:**

Document Name	Version	Date	Description
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There are no items to display

**7.0 Investigator Brochures/Product Monographs:**

Document Name	Version	Date	Description
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There are no items to display

**8.0 Health Canada No Objection Letter (NOL):**

Document Name	Version	Date	Description
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There are no items to display

**9.0 Confidentiality Agreement:**

Document Name	Version	Date	Description
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There are no items to display

**10.0 Conflict of Interest:**

Document Name	Version	Date	Description
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There are no items to display

**11.0 Other Documents:**

*For example, Study Budget, Course Outline, or other documents not mentioned above*

Document Name	Version	Date	Description
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There are no items to display

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Final Page

Status: Approved

**Final Page**

You have reached the end of the ethics application.  
Click 'Continue' or 'Exit' below.

To submit for ethics review, click "SUBMIT for REVIEW" on the left side of the screen.

NOTE: Only the Principal Investigator can submit an application in Pre-submission (ie: the first time it is submitted).

### 7.2.1 Signed Consent Forms

The following is the signed consent form from Lori-Ann Haut. Other consents were taken orally as permitted by ethics board.

**Consent form**  
Interview with experts

**Study Title:** Development of a digital information platform to enhance usability and accessibility for immigrant women who have experienced a miscarriage.

**Principal investigator**  
Mehrnoush Zeidabadi  
3-71B FAB  
University of Alberta  
Edmonton, Alberta, Canada T6G 2E5  
zeidabad@ualberta.ca

**Supervisor**  
Gillian Harvey  
3-77A FAB  
University of Alberta  
Edmonton, Alberta, Canada T6G 2E5  
gharvey@ualberta.ca

Do you understand that you have been asked to be in a research study?  Yes  NO

Have you received and read a copy of the attached information sheet?  Yes  NO

Do you understand the benefits and risks of taking part in this study?  Yes  NO

Have you had an opportunity to ask questions and discuss this research?  Yes  NO

Do you understand that you are free to refuse to participate or withdraw from the research activity until two weeks from the activity without consequences?  Yes  NO

Has the issue of confidentiality been explained to you?  Yes  NO

Do you understand who will have access to your information?  Yes  NO

Do I have your permission to audio record your voice during the interview?  Yes  NO

Do I have your permission to quote you with your real name on my research?  Yes  NO

REB Project Number: Pro00109089

Chapter 7: Appendices

This study was explained to me by the researcher, Mehrnoush Zeidabadi  
I have read and understood the attachment information letter and agree to take part in this study.

Participant's name: LoriAnn Hunt

Signature of the participant:  Date (yyyy-mm-dd): 2021-10-01

I believe the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of the investigator: ..... Date (yyyy-mm-dd): .....

You will receive a signed copy of this form.

REB Project Number: Pro00109089

## 7.2.2 Interview Transcripts

### Genevieve Tam

*Obstetrician/ Gynecologist*

Mehrnoush: How long have you been practicing as an obstetrician?

Genevieve: I graduated in 2013, from residency and then I worked from 2013 to 2016, as an OB GYN, and then after that, I did more of a managerial role. I didn't do as much hands-on patient care. And then I transitioned to kind of public health.

Mehrnoush: How much experience do you have working with women who have miscarried?

Genevieve: Well, through residency, I saw a lot of patients that would come to the emergency room because we did less clinics. So, I feel like every single call shift, I would see at least one, and we would do calls every five, five to six, seven times a month. So, I feel like I had a lot of exposure to women coming through the emergency room. And then when I transitioned to a consultant, I would see probably two or three in the clinic and per day, and that would be like clinic twice a week. And then I would be I would see less of them in the emergency room because I wasn't the resident anymore. I was the consultant. So, it was more like the resident reporting to me.

Mehrnoush: What medical care do you provide for woman who experienced a miscarriage?

Genevieve: So, in general, the standard of care for women who have a non-viable pregnancy is, we offer them three choices like they can do wait and see if the body expels the non-viable pregnancy. Or we can support the expulsion of the non-viable pregnancy with medication or we can offer surgery. A dilatation and curettage to evacuate because it's not it's not safe to have the [the] non-viable products of conception in the uterus for too long, because then it can become [an] a septic abortion and then a big risk to the to the, to the mom.

Mehrnoush: But what if it happens on its own?

Genevieve: Yes. So, when it happens on its own, then we do a follow up to make sure that there's no products of conception that are left in the uterus. Generally, women do not come and follow up if they had a miscarriage. So, if they felt like they had a lot of bleeding, and then the bleeding stopped, and the symptoms go away, we generally don't see them anymore until they're pregnant again, or until they can't get pregnant or something like this. But for the women that still, for example, didn't have too much cramping, didn't have too much, or they continue bleeding after two months, or they start feeling unwell or they have a lot of pain, or what else? Yeah, or if they still have symptoms of pregnancy, for example, then they will come back automatically either through the emergency room or through the clinic. And at that point, we would make sure we get an ultrasound to see what's happening. And then based on the ultrasound, medication or surgery if there's still products of conception remaining in the uterus.

Mehrnoush: Do you think that the care women receive after a miscarriage is enough?

Genevieve: I think it's not. It's not what do you say? It's not continuous. It's not, it's disjointed. It's not, [It's not] a very easy process for women to understand what to do next, or where to go. And then for example, to get an appointment, it's difficult often. And then to and then the [the] issue in Canada is that the ultrasound is a completely different department. And most clinics don't have an ultrasound department

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within them. So, then you have to send them across town. And then you have to find the availability of the ultrasound clinics because in Canada because of public system, there's not enough resources. So that adds to the stress and to the complication and to the trauma of having to go through this experience because they have to go to multiple locations. They have to wait. They don't get the results of the ultrasound right away. They have to wait for a doctor to tell them the results because in North America we're afraid to tell you know anything to patients because they might sue you or they might be misinformed and frustrated. So, for example, I had a chance to be a patient in the European system. And in the European system, the OB GYN have an ultrasound in their in their clinic. So, they're able, for example, if the woman comes and they're saying they have spotting, and there are five or six weeks pregnant, you can go right away and do an ultrasound. Whereas in Canada, if they come on a Friday afternoon, they have spotting, the next available ultrasound will be Monday or Tuesday. And then women are left to going home feeling anxious, not knowing what's going on for the whole weekend. And then they go to the ultrasound, but they still have to wait to see me again, like on the Tuesday because I only have clinic on a Tuesday. And so it's like this whole time, they're in limbo, with no answer, feeling very anxious, reading everything on the internet that they can find. And yeah, left in the dark.

Yes, but yeah, so I feel like, and then when I see them in the emergency room, it was even worse. Because usually, in the nice, I mean, the only good thing about going to the emergency room was eventually they'll get an ultrasound at some point. But then you have to stay to stay with sick people, you have to stay in uncomfortable bed, or even just a chair in the waiting room, and you're exhausted, you're tired, often they may have another child. So, it's very challenging to [to] do that. And then I have to give them the bad news in a very awkward situation. And then I have to plan with them what to do next. And they're tired, they usually already waiting for 20 hours. And then I tell them all you have to take all this medication, you have to, you have to know about these side effects, you have to know how the process goes. And then remember everything I'm telling you. Or I tried to write something on a piece of paper, and then I give it to them. And I'm like, please call your family doctor. I don't know if their family doctor is responsive. Lots of family, doctors don't get scared when it's anything gynecological. And they don't want to do anything about it. And then they have to refer. So, it's [it's] not patient centred or woman centred when it comes to managing anything that's not acute. Right? Anything that's not life threatening. It's, I feel like patients are left in the dark to kind of struggle and manage for themselves.

Mehrnoush: what should be added to the care that women receive?

Genevieve: More resources, more resources more understanding the protocol and how it's going to go. Changing how our system is to align with [with] patient preferences. Because the way our system setup is not efficient, either. It's not like, oh, let's change it just to help the woman. Well, it's actually not efficient for the system at all, either. It's a waste of resources and waste of time and money for everyone. So, if we could, by [by] acknowledging that the system is not working for them, and we could change it, it will actually make the system more efficient in itself and save money, and time and cost. So, what's needed is a streamlined process where if women do present an emergency room, they can go directly to a special clinic where they can deal with everything. And there's continuity of care. And then also provide women with resources so that they can be empowered to learn about it and understand what's going on and make sure those resources are reliable, and not just anything they Google and ensure that those resources are holistic. So, it's addressing all the psychosocial aspects of what they're going through. That is not just a medical issue, per say, like a physical medical issue, but also psychological and social and so forth.

Mehrnoush: Have you ever had an immigrant patient having a miscarriage?

Genevieve: I did residency in Ottawa. So, we did get a lot of, we had a lot of refugees, and also immigrants, less than in other urban centres, I would say But still, there was a there was still a mass. and language barrier and cultural differences often made things more challenging.

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And so, for example, what I mean by cultural barriers is that sometimes they don't communicate exactly what's going on or how they feel. And they always just take the doctor's word at value, and they don't question anything. So then, so then they just don't, if you even if they don't understand the instructions, they might not tell you because they're afraid. And then they suffer at home. And then it delays their [their] management and treatment to care. So, for example, if they have a complication, they're more likely to come later, with a complication, than a non-immigrant who feels more empowered to advocate for their own health. Yes. So essentially, immigrants don't feel empowered to advocate for their own path, because they never did, where they came from. So that's how I feel about that. Although there's different kinds of immigrants, I do have, did experience that sometimes, because they couldn't communicate their feelings with their partners or their family, they felt like being with a doctor who was Western and open to communication, also give them opportunities. So then sometimes they would come more, they would come to my clinic, for example, every day to come and talk about it, which is, the doors are open, but it just made me realize that they didn't have anybody else to communicate their, what they're going through with. And for example, in Canada, psychologists are not covered in most people's plans. Mental health stuff is still very difficult to access. And as already very taboo, is stigmatized in like non-western society cultures. So then just understanding that concept is also already not there. So, there's a lot of education that needs to go around empowerment and understanding your mental health and well-being as a holistic part of your health when it comes to this special minority immigrant populations.

Mehrnoush: Do you think that a digital solution can be useful to women who have experienced a miscarriage?

Genevieve: I think my understanding, I don't have this personal experience of, my understanding with women I've worked with and also friends is that [it's] very people feel ashamed when they've had a miscarriage. And they don't necessarily communicate it. Even my good friends won't even tell me until later, until maybe even there when they're pregnant with the next one. And then it breaks my heart that they couldn't even tell, Tell me. So because of this shame, I think we're having private access to information at their fingertips that can be updated, that can be real time, that can be kept confidential, and also reliable, can really change how women see [this] their situation and empower them to [to] not have to feel the way they feel and to find the right information and resources, more timely fashion.

Mehrnoush: What features do you think that would be most important for an application to have?

Genevieve: I think that what's really, really important to have is to help women acknowledge that what they're going through is, first of all, not unusual. They're not alone. They don't need to be ashamed; they don't need to feel guilt. And then once that part is, is addressed, that they can access resources and help. not just to treat the miscarriage itself, but to also help them process what's going on. Because I think they need to understand that the doctors are not necessarily trained to provide that kind of support. It's very subjective as to which doctor can do it. And secondly, given the nature of our system that they [they] cannot expect to have the kind of care they deserve. Basically, they [they] need to know they deserve more support and care than we can actually provide within our healthcare systems. So, having another resource that's digital, that's that scalable, that's cost effective, can [can] fill this gap that we're not providing for patients.

Mehrnoush: Getting back to features, what features?

Genevieve: addressing the mental health aspect if the feeling of guilt and shame and then explaining what their bodies going to go through. whether or not it's like spontaneous or induced with medication or with surgery. So, having very clear, different kind of sections where it's clear. So if you've already started cramping or bleeding, this is what you're going to go through. And then I'm a little bit biased, because we

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already doing a project like this an abortion, but we've learned that through chatting with women on this app that we've developed for women to have a self-managed abortion, that they are very anxious when the process starts, and they need a lot of support to walk them through the process, because they're like, is it going in the right direction? Is it working? when can I expect it to finish? there's a lot of anxiety around from [from] the start of the miscarriage to or abortion to when it's completed. So, I think there needs to be a feature for that stage. And whether it is something that's holistic that, you know, just reassures them, and then reminds them that it's everything is going well, or if it's some kind of activity that they have to do, or if it's tracking their progress so they can compare day to day. And it also helps if they were to go to a healthcare provider later and say, Look, this is what's been going on. And if their health provider can look, rather than have the woman explain everything back to them, and relive the trauma, that would also help in terms of communication between patient and physician if it comes to that point. But I think having such all these features that help track their progress, and also having a feature that helps them to figure out if it's completed. And when to contact the provider to do an ultrasound and so forth. That would also help alleviate a lot of anxiety, and perhaps even reduce the cost of needing to do ultrasounds because it's there's a lot of research that shows that you can, you can figure out if your abortion is completed on your own without needing an ultrasound. So, if we can show that with induced abortion populations, I think we can definitely do that with miscarriage populations. So, then you could avoid coming to the emergency room, you can avoid a lot of follow up visits and ultrasounds, which are all costly, as well as time consuming for women.

Mehrnoush: Could you explain a little bit more about it? How can women know if their miscarriage is complete?

Genevieve: So, you assess their symptoms as a whole? So it all comes back to their tracking? Right? How has the bleeding been? Was there a point where it's really heavy? Did you feel like you pass clots or things that looks different than clots that could be like the tissue? And then how is the bleeding now? Is it getting less over time? And then when did it stop? And same with the pain, tracking the progress of the pain. It should be getting less and less. And then also tracking the pregnancy symptoms. Is it beginning less than less than so at the end, if you're bleeding is much lighter and almost finished. If there's no pain, there's no fever, and you don't have and, the symptoms are decreasing symptoms can take a bit longer to disappear because the whole corpus luteum that's producing the hormones has to shrink. But as long as things are look improving, like the symptoms are getting better, then basically if they if they do this checklist after two weeks, and they say basically notably saying no to pain, no to fever, no to symptom, you can pretty much guarantee that it's completed.

Mehrnoush: what's the timeline?

Genevieve: Yeah, so we say not to do this checklist before one to two weeks. But the problem is, woman can't wait that long. So then they if they do the checklist too early, it will say Oh, you might still be pregnant. Well, this is at least with the abortion populations.

Mehrnoush: So you're saying that a woman can stay at home and then after a week or two answer the questions and then know if everything is fine?

Genevieve: I think it's possible. I think we need to do the research and see if we can apply it to a miscarriage population, but this is this is validated surveys that they've done already on women who've had a medication abortion. It's a bit different with miscarriage proposition because I think this would work for women who spontaneously miscarry or who need medications to induce the abortion but if they don't have any symptoms, and they haven't used medication then this is also good because it tracks the progress. I've been told that the pregnancy is not viable but I have no bleeding or cramping. This has also helped Because the Texas will say you're pregnant, and then you need to see a provider. So, go to a

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provider. So, this is also helpful for that population. But miscarriage is a bit more nuanced because there's different, different [different] kinds of miscarriages.

Mehrnoush: Do you think women don't freak out to stay and wait?

Genevieve: Yes, it's hard. It's very challenging. But if they can have a tool, a digital tool, they can check in every day, and say, Okay, it looks like there's some progress, good job, not good job. But like, you know, continue what you're doing, you know, remember to take care of yourself, you know, read a book, listen to nice music, eat some food that you like, like things to remind them that take care of themselves other than just focus on this, watch a movie something like this, then they can be reassured.

Mehrnoush: Is there any specific features that an app should have for immigrant women?

Genevieve: resources, resources for immigrant women, like immigrant friendly clinics, immigrant friendly doctors, immigrant support groups, Facebook groups, any resources that can connect them to other people that are from their same culture or would understand what they're going through. Also support groups that are like other women having miscarriages, it doesn't just have to be immigrants, but also going through the same thing. And then [I] we know, that people like chat platforms where they can chat with other people. or we know that they like to hear testimonials about other people who have gone through this. For example, what do people do when they need help? They go to their friends, and then they talk about it. They, you know, ask questions that the friends might not know the answers, but they kind of give feedback, and they give solutions and they provide support. So I think that would be really nice to have on a platform, on a digital two would be to have some kind of forum blog, testimonials, peer-to-peer support.

Mehrnoush: What about language options?

Genevieve: Oh, yeah, for sure. Yes. Language for sure. Oh, illustrations, okay, or more pictures. The pictures also need to represent the different cultures. So more pictures, culturally appropriate pictures, because no, nobody wants to read a lot of text. Maybe videos, and a lot of people respond well to videos, Right?

Mehrnoush: What key health-related or after care information should women know post miscarriage?

Genevieve: Oh, what's really important to know is, I think a lot of women want to know when they can try again. So I think it's a section on when you can start again, because there's a misconception that you need to have, like, you know, three normal periods or something before you try again. And that's not true. To make sure if they want to get pregnant, again, continue their prenatal vitamins. Actually, we always recommend continuing prenatal vitamins postpartum, because you don't have enough time to eat healthy food. And it just kind of keeps you stable. So I think the same should happen when your posts miscarriage to just kind of make sure that you have all the [nutrition] nutrients to keep you strong and healthy. Seeking out extra support if you feel like you've gone through a traumatic experience or didn't have enough support during this miscarriage so that, you know, you can talk about it before the next pregnancy so that you don't have any carryover baggage or burden from it. Information about when to go to that hospital emergency room if there's a complication, I think that's important. So, if they start having fever, it could be related to the miscarriage. if it's within six weeks of it happening, stuff like that. So, what symptoms they should be on [on] the lookout for that could be a complication. Because that information, you know, a doctor will tell you if you see a doctor, when this happens, but then again, it's like you're there's a lot of information you have to absorb, right. So, it would be nice to have it somewhere so that they can refer to it again. I think with Roopan study on my post care for the post-surgical abortion support, a lot of women said that it prevented them from going to the Emergency Room, knowing about

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how it should be after, like the symptoms and the side effects and stuff like this. So, and then, Yeah, addressing their feelings of shame and guilt, and maybe a section on how to communicate this to your friends and family. Because I think people have a hard time. Maybe they want to share, but they don't know how to do it. So, I think they would need more support around that or talking to their partners about it. Yeah.

Mehnoush: In which stage the application should be introduced to women?

Genevieve: As soon as they find out the pregnancy is not viable. Because that's the start of the miscarriage.

Mehnoush: How can we make sure that women know about this application?

Genevieve: Yeah. Yeah, that's I mean, it would have to be, it's definitely a lot of champions in the health care's like sector. So, family Doctor champions, OBGYN champions, emergency room champions, walk in clinics, anywhere where women will show up because ultrasound clinics, anywhere where women basically get the diagnosis. social media, internet, Google. A trusted resource first, like a resource that resource that woman trust, and then they find out about it. So, for example, I guess we, I mean, maybe baby apps, I'm not sure how quickly people go on baby apps. As soon as they find out, they're pregnant. So maybe a baby app would or maybe a menstrual app, like if they're tracking their menstruation on that they get that could be there just so people go back to their app, they know that it's there. Anywhere where people will, will see. Yeah, I don't know. I mean, I guess I'm too old now to know about all this social media, but I'm sure there's something you can leverage on social media about it.

Mehnoush: Are there any medical facts about miscarriage that should be on the app?

Genevieve: Yeah. Like, like when we did our literature review and that, like, you know, a quarter of women suffer from some kind of depression or anxiety related to it. I think this people needs to know that this is not is [is] pretty normal. It's not like normal, but it's happens, happens to a lot of people, and that they're not alone. And that they shouldn't feel guilt or shame. And that they need to get the support so that it doesn't affect them for the future. And what other facts? Yeah, I think that's a really important fact that definitely not out there when you Google. I think other facts to keep in mind are also that, you know, it happens more with age. And that's just the nature of things. It's not, it's not most of the time, it's genetic. It's not what you ate. It's not what you, it's not that you traveled. It's not that you had a massage. It's not that you had a stressful test that day. So, to kind of take away the feeling guilt. I know people still feel guilty, because they're like, Oh, my eggs are not good. But, but in a way, if you tell them this is just normal for this age group, then hopefully, they cannot feel so bad about it.

Mehnoush: May they feel guilty about why didn't get pregnant sooner?

Genevieve: Exactly. But I mean, that's just life. And maybe like adding resources showing other celebrities or famous people that have gone through it would be helpful to know that it just happens to them too. You know, it's not just, Yeah.

Yeah, it's hard. And then maybe, I don't know. Yeah. I would defer to the fertility people on [on] insights around fertility. But yes, maybe something to address that as well. So [so] that people can just make informed decisions.

Mehnoush: Do you have any additional comments that you feel are important to mention?

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Genevieve: No, I mean, I think what's really important is to really acknowledge that the huge component that mental health plays for someone who is going through this experience. And [and] also having an inefficient system in the healthcare within our healthcare system, inefficient process contributes to the mental health outcome. I think we need to put more pressure on the system and providers and say, Look, you are playing a role in their mental health, and that we need to be more accountable. And the reason why we don't make any changes or expend any money on it, because it's a woman issue, I'm sorry. If this was a man issue, there'd be a lot of programs for it. There'd be a lot of things in place. But because it's a woman issue, and you're like, Oh, it's this is just happens, you have to accept it. Women have been accepting this forever, then we just say accept it, or decrease it on the priority list. Right. And like you say, women break through it. And maybe a lot of times they forget about it, and it becomes a non-issue. But at the time, it was an issue. And I think that's what we're not, we're not validating, we're not validating and acknowledging that experience.

## Roopan Gill

*Obstetrician/ gynecologist*

Mehrnoush: How long have you been practicing as an OB GYN?

Roopan: I have been practicing officially as an OB GYN since 2016. So, it has been, how many years? Five years.

Mehrnoush: How much experience do you have working with women who have had a miscarriage?

Roopan: So, it's interesting because I would say in the nature of our practice, it's not like that I have seen patient people that have had miscarriages like as a regular part of my practice, but through residency, you see them a lot in the emergency room. And then also actually during my fellowship, because I did a fellowship and family planning. I spent some time in the early pregnancy loss clinic in Vancouver. And then as my work involves in Toronto right now, I do spend some time working with people who've had miscarriage because I manage them with surgical management.

Mehrnoush: What medical care do you provide for women who experience a miscarriage.

Roopan: So right now, like a lot of my direct like clinical work is with people who have experienced losses is providing them with options, like basically in terms of what like diagnosing and then just like deciding whether it's going to be expected management, medication management, surgical for the most part, I find where I am on that spectrum is to help with the surgical management. So, they usually are seeing an early pregnancy clinic or they've been seen by someone else. And then because I have the skills to do a DNC or surgical like, and they've tried medication, abortion, if it didn't work, then I'm kind of on that side, or medication pills to try to address it. So, I would say that my capacity is more in the treating and doing the surgical.

Mehrnoush: Do you think that what women receive after having a miscarriage is enough in the clinic?

Roopan: No

Mehrnoush: Could you expand on it?

Roopan: I think, interestingly, like a lot of times women who experienced pregnancy loss, they're, you know, in, they come to the emergency room, or they basically are, it's a condition that are not what I want to say it's a condition. Actually, it's a medical issue that is so silenced. And people do like it's also the language we use is always very common. And so I think, because we tried to attach this commonality to it, which is true. And it's, it's to fact, in the midst of that, we kind of forget that it's something that can have impacts on women. Impacts beyond just like that moment when they are going through the miscarriage. So in terms of like, information on their self-care, and how to support them, after a miscarriage, I would say we don't do a good job of doing that, I think we now are getting better in Canada having early pregnancy loss clinics that will diagnose them and like actually take them out of the emergency room where they were historically being managed, but actually being now managed in a in a clinic, where there's nurses and doctors that can help them. But then there's that other aspect of like, ongoing support afterwards, and then preparing them for subsequent pregnancy, we can do better.

Mehrnoush: Have you ever treated immigrant women who have had a miscarriage?

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Roopan: Yeah, I would say, my practice is so diverse of like the types of people have taken care of. So I think that it's been a mix of like immigrant women and Caucasian Canadian women. So yeah.

Mehnroush: Do you feel that the experience is different than a non-immigrant woman? If so, how?

Roopan: that's a very interesting question that I feel like we need to ask immigrant women themselves. Because from my perspective, I would say yes, it is different because a lot of times, I mean, I can just speak for my own community, because I'm the South Asian community, and there's a huge South Asian community and in Canada, is that we, we don't really talk about these, in general, like, issues that happen to us that are sexual reproductive health, that are the problem side, you celebrate birth, and you celebrate the positive things. But when it's related to having an issue, like miscarriage, or an abortion, or you know, a sexually transmitted infection, we kind of manage them in silence. And so I think that there's a component there of like, kind of figuring out how to normalize it within these communities. And in terms of just generally being able to talk about it and opening up that conversation, and then looking at ways that makes it most comfortable for them to do so. So, I mean, I take care of all sorts of people, but I feel like the kinds of support women need it can vary depending on their context and their culture, and where they've come from.

Mehnroush: What is the most challenging part of helping women who have experienced a miscarriage?

Roopan: I think the most challenging aspect, I would say, I mean, sometimes it can be that the process can be drawn out for such a long time. So even if like, you know, you give them a choice, which is great expected, like no, no medication at all, giving them a medication to treat it or then surgical, and then it can be like something where they try medicine doesn't work, and then like it could take some time. So, they're kind of suffering with it for a while. That's one thing. I think the other piece of it, I guess the challenge is that we still can't explain the reasons like I mean, we a lot of times, we say the vast majority of the time, it's unexplained. And that can be a little bit hard for a woman to be like, Oh, well, what do you mean, it's unexplained? So, I think that can be kind of challenging, as well. But that again, it's like that. That's how we counsel people.

Mehnroush: Do you think that a digital solution might be useful to women who have experienced a miscarriage?

Roopan: Yes, definitely. I think it would be for sure.

Mehnroush: What features or content do you think would be most important for the digital solution to include?

Roopan: I think, you know, being able to provide them with self-care tools and things that they can like that can empower them to take care of themselves, physically and mentally, information that's correct about when they can try again to have another pregnancy because a lot of times, they're misinformed, that they have to wait six months, which is not the case, if they're ready, within a month, they can. sound medical information, sound, personal support, I think having a peer-to-peer network within it so that women who've experienced loss can share with other women, their experiences. And then also, I think the other piece that would be great is maybe even like a live chat support for women within the tool. And then connecting them to trusted resources that works for like, wherever they're, [they're] from. So, if it's, you know, Ontario, that they're getting connected to resources in Ontario. And then of course, like considering, like different cultural practices and ways that people think about loss and like grieving and how they deal with that, I think it's important that we don't have like a, just one perspective on it.

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Mehrnoush: You talked about physical and mental support. Could you explain more?

Roopan: I guess, yeah, I run the physical like, what to expect if they're, you know, the different, just like, whether the different if they have the different types of management, like whether it's expected management or with pills or surgery, but like, physically what to expect after the miscarriage is over, and you know, what happens to their body and the changes that they should expect. Mentally, it would be more like, acknowledging that you can feel different feelings and different emotions around a miscarriage, that you're not alone. Like kind of naming those emotions, naming those feelings. Also, recognizing that whoever this tool is created for some people may have this may not be their first miscarriage, it could be that they've had other ones too. So like, yeah, so just acknowledging that there that we need to highlight the mental health support for reproductive health in general. And having that kind of really, I think, the the main focus of this tool.

Mehrnoush: What feature would specifically be most helpful for immigrant women?

Roopan: I think having it in different languages, maybe even having audio features, so allowing people that may not be as literate, that they can actually listen. If you're going to do like a live support or a peer-to-peer support, allowing, making sure that that there is somebody who can represent the community in some way, you know, um, but yeah, just culturally appropriate information within the tool.

Mehrnoush: What key health-related or after care information should women know post miscarriage?

Roopan: Well, I guess, like the changes that happen in their body, some of the mental health issues like, you know that there is a grieving process, that you might feel alone, isolated, guilty, like kind of going through those emotions, and really highlighting that in the in the tool. The need for community and connecting to community and being able to like know that, that there's other people out there that have experienced that themselves, that so there, that's where you can kind of build out that peer-to-peer piece. And then I would say the other part is like, they should know that there are resources out there, but sometimes it feels like they're not that accessible, and that they are available.

Mehrnoush: How about questions that women may have about their bodies?

Roopan: Yes, so I would say I definitely like if they're planning for another pregnancy, like making sure that there's an information within the app that tells or the tool that tells them like, if this is a wanted pregnancy, and they wanted to get pregnant, again, some of the things to prepare their body. So I mean, I would say you'd have to research that a bit more even [even] I would like to want different foods, but folic acid, for example, that they can continue taking folic acid because that's going to be important or their prenatal vitamin. If they're wanting to get pregnant again. And then also information around. Oh, yeah. So when can they hit like likely they'll have their period within that month after the miscarriage and so that they could potentially start again and try again within that month, like after they have that period. I think it would be important to kind of make sure that the, like evidence-based information is provided on the tool and kind of see what's [what's], what kind of information people are providing across the country. And then making sure it's like consistent so that people are getting the right information on the app. But yeah, like other questions, I guess, would be that and then, again, like questions that people have, like about drinking coffee, or like, you know, the kinds of things that they like something, anything that they feel like they did that they're going to blame themselves is important to identify to like demystify, because those are myths, like coffee is not going to put like, you know, tons of how much or like alcohol, like there's certain things Yes, that could cause miscarriage. So kind of demystifying, but then also providing the right information of what are the causes.

Mehrnoush: When do you think women start using the app?

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Roopan: I don't know, I think you need it because yeah, but I think you need it because it's the woman who's had the miscarriage may want to have that information so that it can help her to manage her emotions and not place blame on herself. And then also to prepare for the next subsequent pregnancy if they're planning for another one. So it could be really interesting to have that information, but I would make sure it doesn't emphasize it, it should be a part of that sort of post miscarriage journey of like, Okay, you've gone through the process now kind of is like your last step of like, going through the steps of grief or the steps of like, going through the emotions, but then the last part could be okay, so what's next? Either you're planning the pregnancy or you're not, so you could have a contraception piece because like, if they're not wanting to get pregnant, have the miscarriage, okay, preventing subsequent pregnancy. This is what you could do. And you could either connect them to resources, like the SOG sex and new contraception stuff, or you can take them down the route of like, antenatal like making sure that what they need to do to prenatal care, right, like just making sure preconception that they're taking prenatal vitamin, folic acid and, yeah, and avoiding certain foods or taking good care of themselves.

Mehrnoush: Is there anything else that you want to add?

Roopan: I guess the other part is just like the supportive relationship side, like making sure your partner is supportive, and you could I found, like the work we did on the abortion, having some information that that's for the partner, as well. So not leaving the partner out, I think I've heard that before, that having a section in the app that allows the partner to engage as well, so that they don't, because they also are experiencing this loss with their partner. So that could be really interesting. And that usually is more along the lines of like, how they should take care of themselves and then how to support their partner. Um, I think also the other pieces, like, if they're, I think that's it actually in terms of info, that's what I would say I would say.

Mehrnoush: Should women come back for a follow up after having a miscarriage?

Roopan: So that's a really good question. Usually, we say they don't really need to follow up or they can see their family doctor. or they can like we have the early pregnancy loss clinics so they can be seen there. And usually nurses are calling them, the patients themselves. So the thing is, is that what needs to be considered is that if whoever you're creating this tool for should be accessible for those that are in very in settings that don't have an early pregnancy clinic. In settings where people are going to be like like if they're isolated or in rural areas so that this can kind of act as the support that is a replacement for a follow up. So you don't need that in person follow up that they can have their [answers question] questions answered. But you do need to have follow up for miscarriage management, just to make sure that they've completed the miscarriage especially if they're planning to have another pregnancy and if they've done an expectant or medication abortion. So actually, that's important to think about too, just thinking about it now like because like once the app is they're going to get the app at the point that they have started the miscarriage or see like, what some people so actually that's the thing that maybe it's interesting for you to go through Mehnoush is like, thinking about different women like different types of women. So it could be a woman that's already spontaneous miscarried. And you know when you had it, I did it at home. It was like whatever, did it with me emerge (20:04) like different places women go, you know, some don't go to an early pregnancy clinic, some go to their family doctor. Some will go to a gynecologist. And then some of them are missed abortions where like there's no heart rate, that's the ones that then have different options of how they're going to manage it. So the thing is, is that I guess what, at what point is this going to be used? Is it for those women that completed the [abortion] the miscarriage, and then it's supporting them? Because if it's like they're, if they're going through it still, it's a different thing. So in some ways, I'm thinking that it would be better to consider it for those that have like, had the miscarriage because they're already getting a lot of support, either. I mean, that's the thing that's interesting that we need to like, kind of explore because it's at which point they are getting the tool.

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Mehrnoush: Who should introduce the app?

Roopan: Well, I feel like you know, you should make it open access, like they can find it a search it on a Play Store, right. And so it could be for anyone who's going through a loss, and then they're like looking for a resource, but then you want to be able to also get it in the hands of providers that are seeing patients. Midwives, midwives are a big place, because they're the patients early on. family doctors, obstetrician, gynecologists, nurse practitioners that are working in more rural remote areas. You would put it like I mean, it would be interesting to put into like an [emergency] emergency rooms, right having it like available there as part of a resource that Peds or Doc's can get.

Mehrnoush: You mentioned women need no follow-up after a miscarriage, right? Can they receive all the information they need just from the app?

Roopan: I think [they do i do i] they do need to follow up if they're going through the miscarriage, because like if they've started like, and they're doing expectant management, or [medication or] medication, usually they're being followed by a nurse like or like there should be followed by someone to make sure like either with an ultrasound or with a beta HCG that they've like, completed the miscarriage. So like, because it's also for the woman she will want to know. So if she wants to start to have another pregnancy. But I do think that within the app itself, you could create it in a way that it does provide that it could be I mean, it can be a real, like a tool for follow up in general for people have completed the miscarriage.

And you can provide them with a lot of that information and support, but with the part I'm still kind of figuring out is would it be feasible or like good for those that are in the process of the miscarriage?

Mehrnoush: Do you think that it's feasible if women receive the follow up through the app online?

Roopan: Yeah. So that I think would be more interesting, because what I know from my work is that, like women definitely need, they need to feel like they're, they the app is not going to be sufficient, because they need to feel like they have some access to someone that they can talk to live. So yeah, I think if you had like embedded within there, a live support or some [some] way or someone to contact, like you know, somebody, or that you have people that are on it that can provide the follow up in real time through the app. That's another option. Yeah.

Mehrnoush: Who should be the person they reach out to? An EPL nurse or an OB?

Roopan: Exactly. I think you can do like a nurse, just like how we do it now. Like the nurses how they're already kind of calling patients and following up with patients that their job in the EPL clinics, why would it be nice that you can kind of set it up in a way that the app can be used, and they can connect with these like nurses, even if they're coming from a super rural remote area.

Mehrnoush: Is there anything else that you want to add?

Roopan: I don't think so. It's interesting to like, talk about it. I mean, I know I'm still being interviewed, but like, just like thinking through with you right now.

It would be interesting for you to like, I don't know if I can find a way to get some of these protocols that people are using in the EPL clinics in Vancouver and because I need to remind myself like, what is the follow up process?

I can even ask the one that I work in Toronto, what [what's] their follow up process because that can help to decide at which point is an app beneficial.

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Mehrnoush: yeah. And even Laura, she told me that she has access to EPL nurses. And she said that it would be good for me to talk to them. Because they have first hand experience of dealing with women who have had a miscarriage. So I set up an interview with an EPL Nurse.

Mehrnoush: And are there some surprising medical facts about miscarriage that should be on the app, or would be helpful for women to know.

Roopan: Yeah, so I think like the stuff that I was telling you, like, I'm gonna have to mine the data a little bit too and see, but like, you know, coffee is not the reason that you'll have a miscarriage or like certain foods that you've eaten or not going to be or like, you know, if you exercise [too] too much or travel during the first trimester is not going to cause it right. But I think it's important to highlight like that it's like chromosomal. usually it's a genetic issue. It's not going to make it. So that's why it ends early. It's nature's way of telling you that this was an abnormal pregnancy to start with. Yeah, I think like those would be some of the key things.

Roopan: Yes,. Yeah. So definitely, I think it's important to ask, just share that, to highlight that. It's like, that's how we do with abortion to like to highlight that it is super common, so that people don't feel alone. But then to also highlight that it's like, yes, it's common, but it's okay. Like, it's important to talk about it. You know, like, yeah.

Mehrnoush: Do you have any additional comments that you feel are important to mention?

Roopan: No, but I'm just thinking like, you gave me some ideas myself of making sure that like, because whoever develops the content in the in the app that they're going to develop, I mean, or like, we're going to be hopefully developing it, co-developing it, because vitality, that's what we want to do, is that we really ensure that we get a good, make sure you just collect all the right information. So when the content is being built right now, when you're designing the app, you don't need the content. The nitty gritty content.

Mehrnoush: And you talked about the resources that should be there.

Mehrnoush: Where else women can get comfort from?

Roopan: I guess massage. So like, social workers, psychologists, I mean, OB GYN, midwives, Doulas are really working on this space of like supporting people who've had loss. It'd be interesting to look into that if they are. Like, yeah, we have like pelvic floor physio and like massage and stuff like that the pelvic floor physio is better for people who are like pregnant and like actually going to have delivered. I mean, I'm also like an OB, but I believe in the natural things. So like naturopathic stuff that like, I would, I would just want to make sure that we ask the people who are providing the more support for women after miscarriage, what kind of resources they're suggesting, right? from a medical standpoint, I would say yeah, like Social Work doctors, midwives, EPL clinics.

Mehrnoush: Where can I find, accurate information about physical health?

Roopan: I think you could Google it, and then say, like me, look up. I'm just gonna see BC Women's Hospital, early pregnancy. Yeah, like early pregnancy assessment clinic [clinic], I'm just googling it right

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now. They talk about what they do, then they have more information and frequently asked questions on miscarriage. And there's a video here, I'm going to drop it into chat for you. Okay. They just created this video. I just shared with you.

Meehnoush: And do you have any additional comments that you feel are important to mention?

Roopan: No, I think, I think actually, yeah, like this resource I just shared with you, has like a lot of content that you could actually use. And then think about how you want to Yeah, exactly. And they have like a glossary of terms and the video, and then you can kind of think of how to take that and make it into a nice app.

I would just say, like reference that you're from. Yeah. And then they have like a bereavement line. But this is British Columbia focused. So it's just important to like they have resources written here, because it's all BC Women's Hospital focused. So you just need to look at it. Like maybe the tool you create, maybe you should think about because if you're interviewing a lot of people that are focused in Alberta, then then you should actually design the tool with that in mind, because like you're not getting a cross country perspective.

Roopan: Are most of your people from Edmonton?

Mehrnoush: Yeah, yeah. So do you think that designing an app for women who live in Edmonton is different from designing it for people in other cities?

Roopan: Probably not. I think what will be the only thing that's different is connecting to resources. So you would just need to make sure that the resources you put into the app is more national. And maybe some of the key ones from the different provinces. So I'm just looking at the BC One, they have a BC bereavement line. But does that like does it? Ontario probably has the same. I'm wondering if like, yeah, the other provinces like probably Alberta has one as well. Yeah, there's patient info sheet here too. So I'm sharing with you now, the also the website for the early pregnancy clinic at Mount Sinai Hospital in Toronto, that you can also use.

## Erin Bader

*Obstetrician and Gynecologist*

Mehnoush: How long have you been practicing as an OB GYN?

Erin: for over 12 years as a practicing obstetrician gynecologist.

Mehnoush: How much experience do you have working with women who have miscarried?

Erin: Oh extensive. Yeah, that was part of my daily practice I would say. Like I deal with that almost every day.

Mehnoush: Could you explain more about your experience with them?

Erin: Just in general?

Mehnoush: What is the process and what do you do for them when they have a miscarriage?

Erin: So there's different types of miscarriages. So our, your process would depend on what type of miscarriage it is. People can present with an ultrasound that diagnosed a non-viable fetus or they can present in the miscarriage process, either having completed it or being incomplete. So our involvement would depend on sort of which stage in the process that they are. There's other types of not normal pregnancies that we deal with too that are largely considered losses for most people. A pregnancy that's not in the uterus. We call that ectopic pregnancy. And then there's also something called a molar pregnancy, that's not normal, which wouldn't go on to be a normal baby and so we deal with those as well. In general, for the average miscarriage, there's three ways of managing that. You can manage it expectantly and just wait to see what happens, to see if a woman's body will naturally pass the next normal pregnancy. We can use a medication to induce the miscarriage. Or we can do surgical procedure called the dilation and curettage to evacuate the uterus.

Mehnoush: What care do you provide for women who experience a miscarriage?

Erin: So in our centre, we, like me personally, I refer most people in who I'm involved with to our early pregnancy loss program, which is a nurse and physician run program. The nurses are the people who speak with the patients. But all of the medical advice or, and medical orders are given by a physician. The nurses don't make the plans for what to do, then the nurses present the information to us as a physician, and we make recommendations for how to manage it. Often will give women any of those three options. Sometimes they don't, sometimes we don't recommend certain options. It depends on the clinical scenario, but they may have options. And so the nurses will discuss our recommendation for options and they'll then make sure the patients get the medications and understand how to use them. And then we follow up with them by phone through the miscarriage process. The nurses are available daily in our program, actually there aren't available 24 hours a day, but they're available for sort of 12 hours of the day. And so patients experiencing symptoms that they're unsure of they can actually call the nurses and get to advice by phone and the nurses follow up with them regularly through the miscarriage process to see how they're doing. And we follow their bloodwork and or ultrasounds to make sure the process is complete.

Mehnoush: Do you think that the care women receive is enough?

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Erin: It's very comprehensive, actually and they are provided with bereavement advice as well. It's not just medical advice. There also, the part, one of the one of the other roles of the nurses is to provide emotional support to patients experiencing a miscarriage. And we also then can refer them to other supports if they're having you know, if they have an increased need for emotional support, the nurses can provide other resources for them to reach out too. And then if there's something medically complicated about the patient, they, we will, as physician see them in follow up, but we don't follow up every miscarriage. They're exceedingly common. So, you know, physicians here in Canada, there's actually, we have relatively few physicians per capita in Canada. And so we have comprehensive, multidisciplinary medical teams to provide care, because we can't be everything to all patients. And so we don't necessarily follow up every miscarriages as physicians, like, you know, six, eight weeks later. Because, one, we don't really have capacity to do that, given how common miscarriages are and two because we've done that through our early pregnancy loss program, and people feel very well supported through that program.

Mehnroush: Have you ever had an experience with an immigrant patient experiencing a miscarriage?

Erin: Oh, yeah, all the time.

Mehnroush: Could you tell me more about it?

Erin: So that's sort of normal for me, my [my] patient population is, is largely an immigrant population. I work at the Royal Xander hospital. It's, I'm not sure how familiar you are with Edmonton. I don't know how long you've how long you've lived in Edmonton, or maybe you've lived here your whole life? I don't know.

Mehnroush: two years.

Erin: Yeah. Okay. And so, the Royal Alex hospital is a hospital, located essentially downtown or just north of downtown, depending on what you consider downtown. We're also a high-level referral centre for obstetrics and gynecology. It's considered what we call a tertiary care centre. So the highest level of care that you can get for obstetrics and gynecology in the province. There's only, there are only two tertiary care centres for obstetrics and gynecology and the Royal Alex hospital where I work is one of them. And the foothills Hospital in Calgary is the other one. So we are, we're specialists in complications of obstetrics and gynecology and I have a relatively high risk practice. Because I work at a tertiary referral centre and given the location of the hospital, we, I mean, Edmonton is very multicultural now, I think, in general. Most places, I would say, see a lot of people who are not necessarily Canadian born. But particularly at the Royal Alex, we have a very large immigrant population. And we, I could just consider that normal for me. Like, that's not unusual for me.

Mehnroush: How immigrant women's miscarriage experience is different from a Canadian?

Erin: Well, I think all [all] of our patients are dealt with in the same way. You know, like I said, me personally, all my patients are generally managed through the early pregnancy loss program, and they're not managed any differently. Because they're not Canadian born then if they are Canadian born. We have access to something called the language line at our hospital. And the nurses can do a three way call with an interpreter. And that's, like paid for by the healthcare system. And so they can use a translator in that patient's own language to explain, you know, what to expect in the miscarriage process. Yeah, I would say I mean, so I don't think we treat patients who are immigrants any [any] differently than we treat people who are not immigrants. Often, in my experience, immigrant women have often fewer social supports, because they've you know, they live away from their extended families often and so sometimes that presents challenges in accessing medical care because it, particularly for women, because they're

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primarily they're doing most of the childcare and they might have other children that they need to provide care for. And so that, I mean, this is true for all women, though, it often dictates when they can access and how they can access medical services. And for a lot of our immigrant population, their partners don't necessarily work in Edmonton, so they're often alone here with their children, relying on the support of, of friends and not necessarily extended family. It really depends on the patient's circumstance. I mean, there's lots of Canadian born women, too, that are, are in that situation.

Mehrnoush: What barriers do immigrant women experience to reach their healthcare providers?

Erin: I think a language barrier is probably one of the biggest barriers to accessing medical services and being able to convey what's going on. But that's why we have access to the language line. It's really, really helpful in terms of being able to speak with women, in their own language so that you can get an accurate sense of what's going on, now. Also, women who are new to Edmonton may not understand where to access services. For example, the university hospital doesn't do any obstetrics and gynecology and people who've lived in Edmonton for a long time, they know that. And so if you were, you know, experiencing a miscarriage, you wouldn't go to the [the] University Hospital, probably if you knew that. But people who are new to Edmonton don't necessarily understand that. Yeah. So they may not know where to access the services. But I think our program has actually been around for quite a while now. And so word is kind of getting out about it.

Mehrnoush: Do you think a digital solution can be useful for women who have experienced a miscarriage?

Erin: I think that, yeah, I, in my experience, even people who are extremely low income, they have phones, they have cell phones. And they are really reliant on them. Because they may use friends and family to communicate in a different language for translation. So I do find that your immigrant population is quite reliant on their phones and the ability to be able to access information in their own language, if that is available. If it's translated to their own language. And without them having to go somewhere to access the information that could certainly be helpful.

Mehrnoush: what other features or content do you think would be most important for it to have?

Erin: I would say it would be important [to] for women to understand how common miscarriages are and that miscarriages usually happen, regardless of what you have or have not done. They're not something that you've caused or is under your control. Yeah, a lot of people don't talk about them for whatever reason, and so a lot of women don't understand if they've had a miscarriage for the first time exactly how common they are. I think it's very normal for women to feel responsible or guilty. That they may have caused the miscarriage but that's certainly you know, 99.9% of the time, not the case. And so I think it's really important that women understand that and also that they don't feel alone in the grief process. So I think it'd be important to have links to emotional support for women who are, who have experienced a miscarriage because sometimes people need that. And also access to how, or information on how to access emergency medical care. Miscarriages can I mean they're not usually not here in you know, big city in Canada, but they can be life threatening. They're not usually but they there certainly is potential for excessive blood loss in a miscarriage process and so it's important for women to know when to seek care as well.

Mehrnoush: What features would be most important or helpful for immigrant women?

Erin: I think having the [the] resource in multiple languages, in their own language, I think is important.

Mehrnoush: Is there any specific physical information that women should know about?

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Erin: I guess some, you know, quick points on you know what's expected in the miscarriage process and what's not expected and when that might not be normal and when to seek further medical care. Yeah.

Mehrnoush: and what key health-related information women know post miscarriage?

Erin: So I'm just going to assume that their miscarriage process is complete. It's normal to have bleeding that lasts for a few weeks after the miscarriage process is complete. If that bleeding is ever heavy, and generally we say if you're changing a pad every hour, you need to seek emergency medical care. Usually somebody period, next period will resume in four to six weeks after a miscarriage and as soon as they've had a normal period post miscarriage is okay to try and conceive again. There's no need to delay trying to conceive again after a miscarriage process. We used to in the older days, women were told to wait three months to conceive after a miscarriage. But that's old advice and was largely due to needing to accurately date pregnancies based on when your last menstrual period was but now, we don't like you can date a pregnancy that way. But that's not considered the standard of care. We date pregnancies on early ultrasounds. Yeah. And so it's not necessary for them to have three normal menstrual cycles before conceiving again. After having one miscarriage, your chance of a normal second pregnancy is actually really high. So yeah, I mean, anybody can have a miscarriage. Any pregnancy can result in miscarriage. But after having one miscarriage, you're not at higher risk of having another one. Yeah. So I think women often worry about that.

Mehrnoush: Is there any specific foods to eat or avoid or vitamins to take?

Dr. Bader: So while trying to conceive, there's no foods that we would necessarily say to avoid. we would say to avoid alcohol once you could possibly be pregnant, because alcohol is what's considered a teratogen, which is something that can cause birth defects. But other than that, when trying to conceive, there's no foods to avoid. we do recommend that when women are trying to conceive, they'd be on a full lead containing prenatal vitamin. Ideally, you're on folic acid or folate, that's the same thing, for three months prior to conception, and that's to help decrease a birth defect called a neural tube defect. So you can either take folic acid itself available over the counter or folate containing prenatal vitamin would be important

Mehrnoush: what if they don't plan to get pregnant again, what care they need after a miscarriage?

Erin: So if women don't want to conceive, then yes, they should after having a miscarriage than they should have a discussion with a healthcare provider regarding contraception. Um, yeah, and that's something that we do discuss with people after having a miscarriage if they want to be pregnant or not. A lot of pregnancies like 50% of pregnancies are unintentional. So we would yeah, that would be part of our post miscarriage counseling is if they want contraception. Yeah.

Mehrnoush: When should women come back for a follow up?

Erin: So like I said, we don't necessarily see people for routine follow up after miscarriage. Like after the miscarriage process is complete, we usually do most of our counseling, like during the process, and then immediately after, and we don't necessarily need to see them six to eight weeks after the miscarriage process, unless there's still something that they're wanting to deal with. Yeah, because we could do all of our counseling and, you know, post care instructions more immediately than so many weeks or months after the miscarriage process. The only thing I would say is if they want contraception. We want the miscarriage process to be complete prior to initiating a form of contraception.

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Mehrnoush: If women don't need to come back for a follow up, can they receive all the information they need through the app?

Erin: I guess in general, like general advice, yeah. And I guess I should ask you; you're not putting my medical advice into your app? I just think like that would be something like, because you're a non-medical person, it would have to be reviewed.

Mehrnoush: For sure.

Mehrnoush: What else you think is important to be in the app?

Erin: I would say, either advice on contraception or links to, like, there's lots of things available out there. You don't need to like generate your own information, especially on something as comprehensive as contraception. There's so many things available for contraception. And there's a lot of good resources out there that don't need to be reinvented. And I think just embedding links to reputable resources on things like contraception, would be would be useful.

Mehrnoush: Are there some surprising medical facts about miscarriage that should be on the app?

Erin: I think a lot of people don't understand how common it is. It's estimated that up to 25% of all pregnancies result in miscarriage. Now, that would depend on when the pregnancy is actually diagnosed. Some people don't realize they're pregnant, and they think that bleeding is a late period. And it could have actually been a miscarriage. And so and there's some very, very early losses that happen that people don't recognize that they're pregnant, either. Yeah. So I think the two key points to get across is how common they are. They're not uncommon. This is part of why we have a whole program dedicated to miscarriages at our hospital, you know, two out of the hospitals, like two hospitals in Edmonton have these programs because of how common they are. And that there's nothing that the woman has done to cause the miscarriage. Yeah. Like it's important to, for women to receive that message, because it's normal for women to feel guilty or responsible for having caused a miscarriage, and that's not the case.

Mehrnoush: But you mentioned that in 99% of the cases, women did nothing wrong. What about that one percent?

Dr. Bader: like 99.9%, like oh, like, unless, you know, like, they're, you know, if you the only thing I can think of where you would be responsible for you know, your own miscarriages like extreme drug and alcohol abuse. That's not what we normally see. So I would just say to people like you have not caused this miscarriage and what. So what do you think is a good time for women to receive information about this application when it should be introduced to them? I think if they've been diagnosed with some sort of abnormal pregnancy that will not progress. So when they're diagnosed with a miscarriage, and during the miscarriage process,

Mehrnoush: Do you have any additional comments that you feel are important to mention?

Erin: Um, I would say so miscarriage for women is a really universal thing. And there's not any one group of women that is more likely to have a miscarriage than others. Like immigrant women are not more likely to have a miscarriage. They're more likely to have difficulties accessing care, like you have, I think, touched on and so having a resource that is targeted to them is useful in terms of being I think, providing that information that they may have barriers to accessing, particularly from a language point of view. Yeah, yeah. But they're, they're not more likely to have a miscarriage then then anybody else? Yeah, it's not because they're [they're] new here. Yeah, or anything like that. It's a really universal thing that all women experience.

## Kristine Aanderson

*Psychologist- Specializing in Perinatal Mood Disorders*

Mehnoush: how long have you been practicing as a psychologist?

Kristine: over 10 years.

Mehnoush: Could you tell me a little bit more about your experience?

Kristine: Oh, so I've been a registered psychologist for 10 years and I specialize in perinatal mental health. I was the first psychologist in Western Canada certified by Postpartum Support International, to support moms with perinatal mood concerns. And so I'm super proud of that love working with these moms all the way from, you know, from conception problems, to IVF to pregnancy losses, miscarriage, stillbirth, NICU especially in the postpartum period.

Mehnoush: How much experience do you have specifically working with women who have had a miscarriage?

Kristine: Oh, it's over 1000 by now. A lot.

Mehnoush: How reluctant or willing are women to seek help for their mental health?

Kristine: Quite reluctant

Mehnoush: Why do you think this is?

Kristine: we've got some pretty well researched barriers, but a lot of it comes down to either being able to find the childcare or the assistance and the support, they need to be able to attend the sessions, not being able to know who to go to. And then also just the stigma, there's incredible pressure on moms to be fine, and everything is good, and everything is great, and everything is happy. And if you're undergoing IVF, it's, it's part of your journey. And if you've had a loss, don't worry, at least you can have another one, you know, and so there's just so much pressure to be okay, that for moms to go, Okay, I need to know who to go to, I need the time and the resources to go to them. And I need to feel not stigmatized when I go it's a it's a pretty big hill to climb.

Mehnoush: What therapy tools or approaches do you mainly use to support this population?

Kristine: Generally, I do one of three. And so one is called client centred or person centred counseling. And so that's where the world wants to tell moms and pregnant people how to do their jobs better. And everyone always has a have you thought of this, or maybe you could do this. And so finally having a place that's non-judgmental, where they can be validated in the good, and the bad, and the struggles and the wins, and the losses is sort of what the client centred parties. So it's really kind of holding space and validating what they're going through. And then the second one I use is cognitive behavioral therapy. So that's where a lot of moms will go, you know, my body failed me, my body is broken, I did something wrong. And so we'll do some information around that. And then we'll do some cognitive restructuring in a way that's led by them for what works for them to be able to get rid of some of those negative thought patterns. And then I also do a lot of accelerated resolution therapy. So that's an eye movement-based therapy. That's for trauma and for grief. And it's really good for trauma, grief, depression, anxiety. And it really helps the moms get [get] through some of the difficult parts of this.

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Mehrnoush: Could you explain a little bit more about eye movement-based therapy?

Kristine: Absolutely. So it works on processing out the emotions that have gotten stuck to the event, and then doing a combination of cognitive restructuring and narrative therapy, to be able to work on the bio psychosocial model of trauma to be able to re encode it in the brain in a way that is not distressing for the moms. It's cool. I got certified in it for, I used to work with and I still do veterans and first responders, that sort of 25% of them and 75% moms, and [and] there's so much crossover in terms of the trauma that they have, that it was, it's a perfect fit. So when I started doing it with the moms, I got trained up to the top level to be able to make it really kind of customized for what they need. So it's been great.

Mehrnoush: Are the tools and approaches you use successful?

Kristine: Yes. We find them to be very successful. We [we] don't consider grief to be pathological just by existing. So in terms of does it work? Does it make grief go away? No. Does it, does it get rid of the intrusive images, thoughts, sensations in your body, beliefs about the world? You know, when you're trying to go to sleep, does it help process those out, so that grief can have its natural proper course as it goes through your life? Yes.

Mehrnoush: Is there any way that you can make them work better?

Kristine: The [the] only way that I could make it better is [is] that I'm so sad, I'm in private practice, and these moms have no publicly supported support. So if, if, if you or your spouse has a good Blue Cross plan, or your or you have the funds to be able to do these therapies, they're fantastic. But if you don't, then you're really out of luck. And [and] the difficulty is that perinatal mental health looks a lot like regular mental health, that it's like, oh, I can treat depression. So I can treat perinatal depression. And it's like, no, no, you can't, please don't. they're very different.

Mehrnoush: What are the differences?

Kristine: Some of the major differences are, are in terms of the environmental structural problems that moms have. And so the idea of like, well, let's think of some solutions for your kid not sleeping, and then I'm gonna give you that homework. And then when you can't do the homework, because your child is an independently operating organism that does not submit to your CBT homework, then you're gonna feel like a failure, you're gonna feel like you screwed up, you're gonna feel hopeless, you're gonna feel like you've done it wrong. You know, you've spent all this money and done all this stuff, and it's not working. Whereas realistically, it's a lot of the barriers that exist in the life that can do. I mean, some of it is as small as just being aware of a lot of the pieces. There's a lot of there's a lot of myths and misunderstandings around miscarriage grief, that that you need to you need to know what you're doing. Otherwise, it's really easy to stick your foot so far down your road you can't retrieve it. In terms of there's just a natural want to like, how can we make this better? How can you feel better about this? How can we focus on something that makes you happy? And it's like, I'm in grief. And it's like, well, you know, the baby, you know, it was only six weeks. So, you know, the number of women that come to me saying that a therapist or a social worker, or you know, mental health counselor said the words at least, it's a lot. And then usually it's about six months before they get up the courage to come and try again. So I mean, there's things as small air quotes as that. And then there's some things as big as perinatal OCD manifests in a different part of the brain than then traditional OCD does. And so it's treatments can be somewhat similar. But if you apply out of the box, OCD treatments to perinatal OCD, it ends up not having necessarily the same effectiveness rate. Because the perinatal is a lot based on intrusive thoughts and visualizations.

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And so the traditional like, well, let's just sit with the thoughts if your baby is going to fall down the stairs and smash its head open on the bottom. Let's just sit with that until it doesn't distress you anymore. Is going Yeah, no, no, no mother is ever not going to be distressed with that.

That's not gonna work. So it's anything from relatively small and I mean, even they're things like [like] with, with postpartum OCD was a moms with their intrusive thoughts. Like, you need to be able to keep a pretty cool poker face when the mom when you say, you know if you've been having scary thoughts and she says yes. And then and then the birthing person says yes. And then you say, what are they? And she says, I, you know, think of stabbing my baby's eyeballs out with a pan. Oh, you know, you need to have a pretty good poker face to not be judgmental about that. Because essentially, it's a part of the brain that's focused on protecting the baby. And so it's going, Okay, I've protected against all of these things. Well, what if I was the risk? And so then it's trying to problem solve all those risks. But I mean, if the mom says, you know, you know, I'm thinking about throwing my baby out of the car while I'm driving, you need to recognize it. That's a safety behavior, because she's horrified by it.

And also, because there's postpartum psychosis that some of the symptoms can overlap you. Yeah. So anyway, you need a lot of training to be able to do this one.

And what you do, it's great. It works really well. The recovery rate for moms is extremely high, when they're connected up with, with good supports and resources.

Mehnouch: Do you think having access to resources can help them in the grief process?

Kristine: Yeah, exactly. And so if they have resources and supports, they do really, really well, generally.

Mehnouch: What are the common emotions and fears that women discuss and need support with generally?

Kristine: Definitely the number one is guilt. And because we're so taught that if you just work hard enough, you can find out what went wrong in the world, and you could fix it. And so yeah, guilt is the number one. And then anxiety is another one. grief and depression also come up quite a bit. And then a lot of lack of basic self-care behaviors, like not sleeping, not eating, not taking care of yourself. And we'll even see some like self-punishment of like, well, I don't deserve, you know, my body couldn't hold this baby. So I don't deserve to, you know, have some extra nice salad things or something, I just deserve to sit on the couch and be horrible because my body betrayed me.

Mehnouch: What is your approach when they come to you with these feelings?

Kristine: The first thing that we always always always do is non-judgmental listening. There. We even say like I even say right at the beginning, there is no right or wrong way to grieve. And don't ever let anybody tell you that you're doing it right or doing it wrong, if it feels like it's helpful for you. And so we do lots and lots of non judgmental listening. And then basically, what I really like I like doing client centred care. So I asked them, what would be most helpful like, would they like to, you know, do the restructuring part. would they like to do the ART to remove some of the pointy bits? Would they like to just have someone who, you know, has been there and understands and isn't going to say something stupid, and help them work through their grief, seeing it as a natural process. And then Then I take the lead from the moms, I asked him, you know, what are your goals? What are you hoping to get out of this? layout, the different directions that we could do, and they really enjoy that. Because a lot of times, they're not presented with a lot of options. And so I find, it's really beneficial to be someone who is going in and out, you get to be in the driver's seat, you get to pick the timing, the method, the things like that.

Mehnouch: How do you think a partner can be a part of helping women going through the grief?

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Kristine: The [the] biggest thing is, is that the range of responses in partners is all over the place. And so if the partner is grieving to the same severity as the birthing person is, then then the partner needs to be able to have their own circle of support, so that they each have a different set of people to be able to go to, and then come back together to be able to watch a movie or, you know, do stuff like that, rather than you know, let's work on our grief together per say (And so there are responses all the way to that. There are some folks that just don't know what to do. So I basically make them, I call them cheat sheets, or, or cheat codes from video games terminology, which is just basically going if she's crying, what do I do? Place a hand, and we work with the birthing persons to make these flowcharts we're going to, place your hand on her back and sit down next to her. Ask her if there anything she needs in this moment. If she says no, go and get her a cup of tea. if she says yes, you know, do that. if she says, Oh, I'm if she brings up feelings or emotions, do reflective listening, and I will teach the spouse how to do reflective listening of like, Yeah, it sounds like it's really hard that you're dealing with this because a lot of spouses want to fix it. And because society is trained that men's job is to make women stop crying. And so I'll give them these cheat sheets, and it's fantastic. It also can, it can also help head off resentment, because especially if the birthing person is, is grieving quite heavily, and the other partner because it was more abstract to them as compared to real, you know, air quotes real. Then there could be some resentment when the first things like well, you know, come on, it's been a month, it's been two months, it's been four months. I've moved on. And even if they're really nice, there's that pressure of like, well, he seems like he's fine. He doesn't care or she doesn't care. You know, she's just moved on. And then like, it's okay. And so you can get a lot of resentment with that. So I find if [if] the other spouse is not heavily affected by it, being able to train them sort of in basic mental health first aid for support is incredibly helpful. And the guys love it, too. Because they're like, oh, yeah, I know what the right answer is.

Mehrnoush: Are you familiar with any digital solution for dealing with grief?

Kristine: I'm not aware of a lot of them. Hyperemesis Gravidarum, which is basically barfing your brains out during pregnancy, has a really nice apps that they have. But I've not seen a ton of really good ones for grief, because it's so nebulous and individual. It's kind of not a, you know, a one size fits all sort of thing.

Mehrnoush: How the app you mentioned is helpful?

Kristine: Well, I'll answer for the one that the VA in the States has some really nice ones. The VA has a mindfulness app, that you can choose just basic mindfulness meditations. And, and they can be like body scans, or they can be you're on a beach in Hawaii. And it's nice, cuz you can pick a five one, 10 minute one, sleep one, and then it automatically shuts off when you're done. And so that's a really nice one to be able to go, you know, and have that mindfulness sort of based stuff that I can just like, click on and go. Alright, I want to do the Hawaii one. then body stuff or, like beach in Hawaii, you're in space riding unicorns. And then, on top of that, a lot of people on especially it's a phase of grief, that's quite painful. The idea and especially if there's anger and frustration, the idea of doing a mindfulness app, they just can't stand. And so there's actually a hysterical one online on YouTube. And Pardon the language but it's called fuck that a guided meditation. And so it is done absolutely correctly, like a guided meditation, but it's saying, you know, breathe in lightness, and breathe out all that bullshit. And so it's got a bit of comedy and a bit of crassness to it. And I've been able to have a lot of moms be able to identify with that, and be able to be the gateway into that sort of stuff. So that is helpful too.

Mehrnoush: How can an application help woman who have experienced a miscarriage?

Kristine: I think essentially, it needs to be something that is targeted towards moms. And I mean, sorry, birthing persons. Because they're, there's such an odd collection of like, okay, you can go to this website,

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you can read this book, there's this podcast, there's this whatever, you know, old, go to the mindfulness app, or watch this funny video on YouTube. Because I mean, like, we know, cats falling off coffee tables on YouTube causes mood improvement, but, but they're all sort of all over the place. And, and if you're in that grief, or that trauma, or that stress, or holy man, pregnancy after miscarriage can be a nightmare if you don't get it treated first. The idea of okay, well, now I need to pick between these six resources and look it up and go find it. It's just It's overwhelming. So people just don't do anything and just sit on the couch and cry.

Mehrnoush: What other features or content do you think would be most important for it to include?

Kristine: I think, I think having a resources section, there's an amazing website called Return to hope, which is all about supporting parents through loss at any stage. And there's, there's like some good books. And so I think, having resources and it would be amazing. Having mindfulness materials, especially for like going to sleep would be huge, and like, like an hour and a half long, guided meditation to go to sleep with something that contains no triggering information about babies or children or kittens or puppies, or you know, that would be really good. The spouses cheat sheets would be fantastic to have in there. And even kind of a flowchart with sort of coping skills of like, how am I feeling? You know, if we say, we affectionately say the cast of insight out, happy, angry, sad, afraid, worried, disgusted. And then having a bit of like, you know, like, click on that. And then it says, do you want to have your feelings feel validated? Do you want to change how you feel? Do you want to, you know, whatever. And then you can click on that, and then it would direct you to the correct, I mean, correctish, sort of thing. And then having just the base information on the front, so being able to go like, there's no right and wrong way to grieve. Here's like, 101. Because you know, the hospitals do a really great job, but then they send you home. They're like, Alright, bye. Call me when you're pregnant again, just be like, Oh, okay.

Mehrnoush: Do you think women are receiving enough care that they need from their healthcare providers after having a miscarriage?

Kristine: Absolutely not. No, um, there are early loss facilitators out of the Grey Nuns and out of the Royal Alex. And mostly, they're very good. You didn't hear it from me, but a couple of them are not great. They're mostly pretty good, but they'll [they'll] follow you for like two or three weeks. And then the problem is that if they have to refer you to somewhere, they can't, because there's nowhere public and they're not allowed to recommend private. So it's sort of like that like, Okay, well, and you know, and it's really sweet. They send you like a little seed packet of forget me nots, and, you know, like little basic brochures. So I mean, they've got some supports in place. But I think especially for, for the ongoing care for early loss, pregnancy after early loss, Holy Hannah is that important because that's super highly correlated with postpartum anxiety and depression. And [and] Peri partum anxiety and depression for sure. So following them through that, but also like, the sort of late term losses, you know, there's so much information that they need and support that they need and at the hospital, they're like here, we're here for you and we do all this stuff and then they just kind of send you home and say, you know, here's [here's] some lost people if you want to call them and they'll talk to you, you know, for half an hour an hour on the phone, but there's, there's a lot more moms need, you know I have right now I've actually got like five women that I'm seeing like that have just started for all losses between like 19 and 24 weeks. And all they suffer, all they suffer.

Mehrnoush: Do you think that is it different if women lose their babies when they are in the earliest stage compare to being in the fourth or fifth month?

Kristine: Generally [generally] not. There's, there's generally not a difference in grief. Because basically, there is the grief of essentially those cells, no matter how many of them there were at the time, but the thing that often is extremely painful, is the loss of what we call imagined futures. And so what that

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is, is that when you are eight weeks pregnant, you are not, you know, 144 cells pregnant. You are, you know, eight months away from your baby in May, and so it's gonna be spring. So I've already started buying some clothes, and we're gonna need a jogging stroller. And so that's, you know, as soon as you know, they calculate your due date, you're imagining, oh, a Christmas baby. So we'll have to get this stuff. And, oh, we'll be parents and when will my mat leave be. And so there's this whole like, one to two years of your life that you spool out ahead of you where that baby is as real as if it was with you. And then when you have a loss, it's gone. And it doesn't matter if that loss, you had that that imagined future that made you so happy for six weeks or six months. The [the] grief in that part of it tends to be quite similar. The [the] only differences that we see is, is that trauma tends to be a lot more common with the later losses. Because there's usually periods of uncertainty, there's usually all we need to do some tests, there's usually sometimes some sort of life saving or pregnancy prolonging attempts that are made, which are usually quite harried. Lots of uncertainty, lots of unknowns, and then and then basically delivering a baby that that once they're past like 1920 weeks, they're alive when you deliver them. And so you get induced because your body does not want to have a baby at 20 weeks. And then induce Labors are always hard. And then they you deliver this baby knowing that it's gonna die. And they wrap it up, and they put it in your arms and it's alive. And it's perfect and has little nose, little fingers and looks like a perfectly healthy baby, because usually it is and [and] then you hold it in your arms while it dies. So a lot of trauma. It's not necessarily that that means those people have more or less grief. But in terms of traumatic imagery, intrusive memories, avoidance, hyper vigilance, we tend to see a lot more of that in the later losses.

Mehrnoush: Do you think that the app should have different sections for early pregnancy loss compare to when they are experiencing a loss in late months?

Kristine: I [I] think I would definitely lean towards it being the same. Because if you're in that no man's land that you were, like, 12 weeks, 13 weeks. So it's not quite either way. It can be really stigmatizing to have sort of, oh, no, we're gonna categorize you based on your loss. But I think being able to provide categories based on experiences and resources from experiences. So having a section of, you know, did you have to be induced at a hospital? You know, were you given medications to take at home? To do that. Were you engaged in watchful waiting? So I think being able to identify the different things that the grief can sort of get stuck on to as the resource points rather than the number of weeks I think would be really beneficial for everybody because if a woman had a dramatic delivery of you know, a 22 week and that then died, she will really quickly push on the button of like, Did you deliver your you know, your baby in the hospital? Yeah, I did, or it was a non-viable. And then and then there we go, oh, well, no, that wasn't me. So it's not stigmatizing to not be included. You know? I could talk about this for days.

Mehrnoush: What is your opinion on being in touch with other women who have had the same experience?

Kristine: I think what would be really good is to be able to be put in touch with, um. The truth, it needs to be moderated. Because things can go badly when you are with other women who have also experienced losses. Because like, if you have had, if you're on a first time loss, and you're in a group with a woman who has had six losses, then as the person with the first time lost, your brain is immediately going to go to oh my god, I might have five more miscarriages. But I think being able to, if there is any way to like either with return to hope or return to zero, I keep forgetting their name. Essentially being paired with sort of mentors, with like, here's some women who have been through this, whether it's through a Facebook group or through whatever I think someone who's kind of on the other side of it, but knows what it's like. Like peer helper might be really good and Postpartum Support international's got a really great peer network.

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And they have a weekly like calling chats, as well, where people can call in and there's one for dads and one for moms and one for loss and one for NICU and one in Spanish. And it's really good.

Mehrnoush: How can we best support the mental health of women who experienced miscarriage?

Kristine: Um, I think being able to provide them the information that sort of it's there when they need it. The one I really like is Dr. cat that has a podcast called mom in mind that deals with miscarriage and grief sometimes. She says that we always want moms to have this information at their fingertips before they need it. And so being able to have the information is great. Being able to have quick, easy, clickable access to tools would be amazing. And with [with] a little bit of guidance of like, are you looking to feel more relaxed, you know, or whatever, that can help sort of guide them of which [which] tool might be the best? And then they can kind of do that picking like I do in my sessions would be amazing. What else? I think that's all I've got for in terms of that piece.

Mehrnoush: Is there anything to be mindful of specifically when working with immigrants' women?

Kristine: One of the things that's really important is that different cultures all over the world, and even different cultural basis within, you know, apparently heterogeneous populations, like white or Indian. There's tons of cultural differences that you can't tell. And so being really, really cognizant of those individual things. And so just being able to ask some of the questions like, you know, how do you feel that the culture you grew up in, or the culture of your support system is influencing, how it's going or what's happening. Because some cultures really, really shift to kind of the blameless models, some are very frankly Blamy. And so that's, that's kind of tricky. And some of them, it's like one of my trainings was in New York and in through orthodox [Orthodox] Judaism, it's not considered a baby until it takes its first breath. So you're not entitled to the regular grieving procedures, until it's taken its first breath. So there's some really wonky sort of things. And so trying to be able to just incorporate essentially an multicultural lens. I think it needs to just [just] basically try and hit as many pieces that are going to cover as many of the different multicultural aspects as possible. And [and] addressing the different ease of support. So going, some people have tons of community supports, and it's great. It's wonderful, and some people have none. And so if there's a worksheet that's like, you know, here are 10 spots to list all of the community supports that you could ask in your family for help and there are 10 spots to answer. It's like, oh, that's not very culturally sensitive.

Mehrnoush: What barriers immigrants women face in Edmonton after their miscarriage compared to their native country?

Kristine: a lot of times what we see that's really difficult is North America really quite garbagy frankly. we sort of have this fortress mom and dad mentality, that it's like, no, no, it should just be like the two parents, and maybe the grandparents, you know. And so we, a lot of times, practitioners of Caucasian descent, will assume that they will assume that that is the norm. And so if someone talks about, you know, I'm really stressed, and I feel so bad, because all I have is me and my partner and my parents that live in the house, if that's normal in your culture, you might go, oh, that sounds like you've got great supports, but if they came from a community with, you know, 30 or 40 extended family, you know, having three people feels like, you know, you're completely isolated in the middle of nowhere. Um, the, the other one that I do find is, is that population that's really stigmatized through miscarriage is the LGBTQ two s plus ones as well. So I think there's, there's just it's always tricky with language. And because it specifically with that population, it's really hard because a lot of times, society doesn't want to call parents who have had miscarriage and have no living children, they don't want to call the moms. But they really want that. They're like, No, I am a mom, I gave birth to a baby or I had a baby or I was pregnant. I am a mom. But mom can also be a really stigmatizing thing. If you're transgender, if you are, you know, with these different sorts of things. So it's like, oh, shoot, so I shouldn't say birthing persons. But if I say birthing

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persons, then that might make it difficult for people who is prior to 12 weeks where it wasn't really a birth, it was more at home. So I mean, there's, there's [there's] a lot of tricky things where it's easy to in trying to fix one thing, you step on another thing. That's where it's difficult with an app compared to an individual's because my job is easy. I just say, What would you like me to refer this as? Do you want me to call it a baby, an embryo, a collection of cells, your daughter, the name you chose for it? Like, what do you want? What do you want me to refer to you to you as mom? pregnant person? Like, what? What do you want to be called? So I mean, it's easy for me, because then I just write it down in my notes, and I just do it every time they come in. But on an app, it's [it's] just something that's that is probably just going to have to be kept an eye on and just, you know, sent out to various communities to be able to go, Okay, what blind spots did I miss? Because it's not actually possible for one person from any community to be able to get this right on the first crack.

Mehrnoush: How do you think I can address this problem in the app?

Kristine: In terms of solving the problem in the app? See, this is where I only know the magic of computers. So I don't know if it's possible to like, if you can click a button, and that would change the terminology in the resources. So it would say mom, or it would say birthing person, or it would say embryo or baby or collection of cells, or your child or your daughter or your son, Yeah, with the magic of computers, I have no idea if that's possible or not. But it'd be nice because then if someone finds, you know, the, the your baby or your child to be really inclusive language, and then all of the information just says that it really is helpful for validating and things like that. But I mean, I have no idea what, how you do that computer rhythmically.

Mehrnoush: Do you have any additional comments that you feel are important to mention?

Kristine: Oh, I could go on for days, what would you like? I think basically having [just] just really easy sort of accessible tools. One, that one that we have is the, there are lovely webcams all over the world of like the sea otters at the Monterey Bay Aquarium, or, you know, any of that kind of stuff, the guided meditation stuffs and these stuffs and resources and definitely being connected to resources would be really good too. Oh, and then some Oh, that's what it was. Do you know about the app/ web program that's called, Oh, what's it called? Better get better? Real? Better? Super better? There it is. Do you know about that one?

Mehrnoush: No. could you tell me about it?

Kristine: Yes, super better is amazing. Because basically, it's it sort of it came out of the gamifying movement. So it's, it's a little bit like language for video games, which we obviously don't need to do. But it's got such beautiful roots of like, you can you can say I'm depressed, I'm anxious. I'm sad, you know, whatever. Or you can do custom goals. And then you set out what are your bad guys are you're [your] challenges or your bosses, which is you know, Oh, it's you know, dealing with this or dealing with that. You know, who were some of you're [your] sidekicks who you can call and so there's some really fun, and then you log on, and every time you log in, you get points. And then the points, you know, you can turn things different colours. And that says, it tracks some of your progress to say, how is it going? So anyway, so super better is amazing. It's so good. I use it a ton with teens. And if there was sort of a way to use that sort of base algorithm with the mom stuff, that would be amazing. Because yeah, tracking progress is really good, too. Oh, and then having something for what's normal and what's not. So essentially the [the], is this normal, or should I seek help? is fantastic. Because I've had, I've had some moms where this is more about postpartum where the postpartum moms will say, Yeah, you know, I had the baby blues. So what did that feel like? And they go well, you know, I was crying every day for the first six months and I'm like, That is not the baby blues because the [the] baby blues is basically high levels of mood volatility for the first two weeks. And [and] we always screen for it is that the predominant mood is happy. So yes,

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you're crying, because you know, they're going to graduate and go off to college one day and you'll not have this adorable baby with you anymore. And now you're just sobbing for no reason. Like, you know, there's that sort of stuff but the predominant mood over time is happy. And [and] moms don't know what's normal and what's not. And so being able to catch something because generally I see moms when it has gotten completely unbearable.

Mehrnoush: Do you think it is possible for a digital tool to evaluate women's mental health and refer them to a psychologist if they need help?

Kristine: Oh, that would be fantastic. I think either [either], I mean, again, computers are amazing, either being able to have an algorithm so you can just start with how are you feeling? And then if it's sad, has it been more than two weeks or less than two weeks of every day or almost every day? Or anxious? Has it been interfering with your ability to do regular things in your life? [The] for you to be able to see what it is either I could walk you through it, or Postpartum Support International has beautiful definitions and our diagnostics, just manual five, the DSM five has like the diagnostic criteria. And as long as you call everything a screener, then then it just says, you know, this is a screener. So you might want to go talk to somebody about this. And I've got, if you want to ping me with an email to remind me I have is called the Anderson perinatal screener, where I basically took the [the] 10 most common perinatal mood disorders and smashed them all together into one quick screener that, that is sort of like a base thing. So [so] as a clean screener doesn't mean there's no problem. But it's very often that when something is going not great, that it's like, well, there are these symptoms of depression, but these symptoms of anxiety well, but their eating is also deteriorated and their trauma symptoms. And so being able to have something that can sort of guide them through these different things and be able to go, this might be a time where, where you might want some help, like if [if] someone has been working on the same, you know, grief module or whatever, even if there are modules, it doesn't make any sense. But like if they're working on the same piece, and they've been working on it for more than four weeks, having a little pop up that says, you know, if something's, say, stuck for longer than two, four weeks, that might be a time to, you know, touch base with a professional and ask them you know, if there's anything that any specific, you know, treatments or tools that we can use to help you feel better. Oh, the other thing for you to look at is, is that there is a, I think she's on Instagram, she's called the latest Kate. And she makes these adorable illustrations of like cute animals that say, like, you know, today may be tough, but you're gonna get through it, and you still have value or something like that with a cute picture of like a pink otter. And I'll give moms a lot of those. So even having like cute printable that are like encouragement things that might be helpful to

Kristine: And [and] the other thing in terms of grief is back in the day, we used to have the grief model that was that was get over it. And the sooner you can get over it, and we all stop talking about it, the better society will be. We now know through research that that traumatizes a ton of people. So we've moved on to the [the] one called continuing bonds. So anything that we can do to help facilitate the [the] continuance of the existence of baby tend to be pretty helpful. That's why they do the Forget me not seeds. With the early loss clinic. I know lots of parents that plant trees. I know ones that make like baby books, there's some beautiful books about [about] like miscarriage and loss. And so sort of anything that can help facilitate that continuing bonds that like no, no, this will always have been one of your children. And that's okay. And some way to even commemorate that, or how can we continue that if they want it, then then that can be helpful too. Oh, and just a side note, physical things that are normal and not normal. That would be really good. A lot of moms are like, they didn't mention that I might bleed for two months.

Mehrnoush: Could you tell me what physical questions women generally have?

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Kristine: it's [it's] so much what is normal and what is not normal? Um you know, is it dangerous to have sex at certain times? I mean that's a little bit of one but it's mostly like [when] How long is it normal to bleed for. How long do you air quotes have to wait before trying again, you know. If there are any pelvic floor symptoms or things like that or tightness or you know essentially that and that would be more of talking to either a, like a pelvic physio or like a good OB to ask them of going so let's have a section for these are normal physical things and these are not normal physical things. So generally, that would be after they've had the miscarriage or the Oh, you could also have a section which would be amazing. That is like because a lot of times they'll do watchful waiting so you know your baby's dead. but we're gonna see if your body's gonna have a natural miscarriage or if we're gonna have to help it along which ends up being were first like two days to three weeks of some one's life.

## Patti Walker

*Grief counselor/ founder of the ParentCare Society of Edmonton*

Mehrnoush: Just for the record, could you please tell me your name and your position.

Patti: So my name is Patti Walker. And I am a nurse, and I'm called the regional bereavement coordinator based out of the hospital for the women at Royal Alexandra hospital. And I'm also the facilitator for the parents care support group.

Mehrnoush: How long have you been practicing as a social worker? How much experience do you have working with women who have miscarried?

Patti: Okay, so I'm actually nurse, not a social worker. And I've been facilitating the group now for about 23 years, and I've been in the position as the bereavement coordinator for 14 years.

Mehrnoush: That's great. Thank you so much. And where have you found that women get the information they need from?

Patti: Oh, in regards to a miscarriage?

Mehrnoush: Yes

Patti: A lot of times it is found, like if they deliver at the hospital, they are given a little bit of information about where do you start finding, but a lot of it is by Google, by social media, and then also family and friends. Not so much from the doctors.

Mehrnoush: Do you think that it is reliable information?

Patti: Not always

Mehrnoush: Why?

Patti: Because number one on there's lots. As we know, there's lots of misinformation on the internet. And I think also with, ... when you're talking to family and friends, sometimes it's not always reliable information. It is stories that have been passed down, culturally and generationally. And it's not always true. Part of my role is to do counseling with women. And so I listened to what their story is in that and sometimes a lot of the questions that women have is, you know, why did this happen? What caused this? And a lot of times, they have a lot of really wrong information about why this happened. Majority reason it's not their fault. And some of these cultural things, you ate a certain thing or you slept a certain way, cause a miscarriage and so head and heart aren't always matching. But there's no scientific based evidence behind any of that.

Mehrnoush: And do you think what barriers women experience to reach their health healthcare providers, you mentioned that they don't receive that much information from them? Yeah. Do you think that is there any barrier for women to reach them?

Patti: Well, I think a lot of times a lot of the medical professional medicalize a miscarriage they will give the statistics that happens one in four That it's very common, that it can happen to anyone that it may not continue on, you know, for their next baby and that, but it's not what the women feel because they don't

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want to know about their next baby, they want to know about the baby that they've lost. And it's also a difference if it's a loss for a pregnancy versus the loss of a baby. So that also needs to be supported. But I think for medical professionals, they will use language that is not always supportive. And so I think again, need to definitely meet the women where they're at, I think it's improved over the last 14 years, it's definitely, you know, part of the reason why I do this is because I had a miscarriage myself, and I came from that medical background is a little bit as well. But the support has definitely improved over the years. And I think a lot of it is that peer support. And so sometimes where to find that peer support that is, again, appropriate support as well is so important for women, because it's very isolating experience. And it gives them the opportunity to share their stories and if necessary, share their babies, as well. Again, sometimes women will miscarry at home, and they may not even see a healthcare provider. And so again, that's a very isolating experience as well. And family and friends sometimes will just say that, you know, it wasn't meant to be or you can have another baby. And again, that really disenfranchises them from the experience.

Mehnouch: Is there any specific barrier faced by those women because they are immigrants? Are there any differences?

Patti: I do think I mean, not being an immigrant woman and not having gone through this, I can only talk about what has been taught to me. But I think a lot of times if English isn't their first language, there can be a lot of barriers that way, again, sometimes the cultural or the family expectations can really impede that. Because I'm you know, I've had some cultures that have said, Well, it's because you ate a mango or was because you [you] know and [and] this is not true. But that has been passed down from generation to generation. We do know that there can be some foods that can contribute to miscarriages, but not cause miscarriages. But those are based on scientific based evidence behind that. But so again, there's a lot of misinformation out there. There's a lot of myths. And I think that's if you don't have a good group of support, if you're just dealing with women, or a culture or the immigrant community that you're with, and if they don't have that evidence behind that, because it's never been shared with them. And I think that that's not an ignorant thing. It's not out of ignorance. It's just if you if you don't know the information, then how can you share that information? Right?

Mehnouch: How immigrant women's experience with healthcare is different in Canada compared to their native country?

Patti: I think there can be some definite differences, especially like I've had some women that have gone through a fertility journey that, you know, a long time expecting to get pregnant. And there's a few different countries that I can think of, but they don't understand why we don't do all the testing here in Canada. Why we you know, what were impossibly in their home country, some other testing in that may be done. So there's a difference in the healthcare systems as well. Also, sometimes it's difficult if it's difficult to find a physician in Canada, in Alberta, and especially one that speaks your language might make it more difficult. So that increases quite a barrier for women, I imagine because I know that it is difficult to find a doctor at the best of times, but one that speaks your language if English isn't your first language.

Mehnouch: Are there any stories that you can share with me?

Patti: Well, I'm just again, in very general terms, I find that a lot of times, some cultures or some expectations is that you just, maybe they come from a background or there were many, you know, it was common to have losses, or you know, you have common to have many pregnancies and with the more pregnancies you have the greater risk, you have a loss, it's just a statistical thing, nothing to do with how wanted these babies are, that I think there's sometimes just expected to just move on and go into another pregnancy quite quickly, and doesn't give them the opportunity to grieve that that experience and some

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sometimes I have found that, you know, they've talked to their, their faith community, or they, they've spoken to their mothers, their sisters, and that and, but that's not what they're feeling. And they don't necessarily, if you don't have somebody that's open and willing to talk about that, it just adds that much more to the isolation to it. And so like in the support group, it's getting definitely a little more diverse in the ethnicity and the cultures that we're having to share. And so I'm always having every, every woman teaching me something different, I have just one woman who's very outspoken in her community, she's a Muslim woman, and she has shown me some websites in that, that are really nice, supportive websites that I can pass on to other people. And so, again, if we create that circle of support, because I, I do not know it all, I'm very open to find out other things. And I just recently been finding, like, French speaking resources and Spanish speaking resources. And that, so try, so I, I have a little list of all the different opportunities, you know, anything that I can gather, maybe pass along, as well to other people as well.

Mehnoush: Who are the first people women connect for support and they feel comfortable with? Is there any differences for immigrant women?

Patti: Um, I think there might be minor differences. I think it's [it's] very much women supporting women. I mean, it's parents supporting parents as well. But I think sometimes it's, it's creating that village of support of the women, but the people that you hope or thought might be your best support, whether it's your mother, whether it's your sister might not be. So they might be putting up some of those barriers, not necessarily intentionally, but it means that, well, I don't want to upset them. So I can't really share what I'm going to share. And so finding a neutral person, whether you're an immigrant woman, or any woman, I think is very, very beneficial. It's [it's] a really crappy club that they've joined. But when you add in the fact that you're an immigrant woman, and even have other layers to that, that even creates more isolation. So just want to be able to create that support for [for] women so that every woman, if she chooses to has the opportunity to talk to a safe person. And some people will just say, you know, this was sad, this has happened, I want to get into another pregnancy. And they don't. They're sad in the moment, but they may not be sad later on. And so we shouldn't be telling them that they have to be sad later on. Because that's what their experiences for sure.

Mehnoush: Do you think all women know about these support groups?

Patti: I think, hopefully they have the opportunity to know about the different support groups, but whether they feel comfortable going to the different support groups, and now especially with COVID, and we're not meeting in person, it's we're still meeting by zoom, that has been beneficial and not beneficial, because it gives you that anonymity a little bit. So even in a zoom meeting, you can turn off your camera or if you join, like a close Facebook group, then you have the opportunity of never posting but always reading and getting other resources and so that can take away some of the loneliness as well. I do sadly, I do know that there's many women that are not informed about these different opportunities, and I think the We talked about it, the more because the reality is there will be more another woman that has a miscarriage. And so if she's given that opportunity to know of these options, then maybe we can take away some of that isolation for her as well. And I think some of the junk to know about the different supports that are out there, again, it comes from that Google internet research that social media, but not everybody's on, you know, on social media as well. Hopefully, their doctors are telling them about that, or the early pregnancy loss programs of the two hospitals or, you know, at the time of the loss, if they come into the hospital, they're given the information. Sadly, I know, that isn't always happening. But I was starting to do that. And again, if a woman doesn't speak English or English is her second language, I use translator services quite a bit. But I, you know, honestly, I don't have many ESL women that I support for the counseling part. And I'm assuming, but I don't want to assume that maybe they're just not comfortable with speaking to someone that doesn't speak their language and using somebody as an interpreter in between.

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Mehrnoush: What post procedures support women expect to receive, but they don't receive after the experience?

Patti: Well, I think a lot of times, if it's right at the time, when the most kids are so overwhelmed by all the [the] actual events that they're going through that, hopefully they realize that if they're given the information in the hospital, that it doesn't have to be immediately post loss, it can be, you know, a week later, a month later, even a year later, they need to reach out. But again, human nature is you don't always reach out to somebody if you don't know who they are. I mean, it's just a name on a piece of paper or a voice on the end of the phone. So that human connection, so that's where COVID has not been great. But that human connection is can go a long way in supporting women as well.

Mehrnoush: Do you think women are receiving enough care?

Patti: I think they're not receiving it enough. Hopefully they're receiving some. But I think that the definitely it could be improved, especially for immigrant woman because I can match.

Mehrnoush: How?

Patti: I don't know if we need to get more resources in different languages, or other websites that are appropriate for different people or, you know, partly from your research, if we find other, you know, gaps in the service as well.

Mehrnoush: What support are most important for women who experienced a miscarriage to receive?

Patti: I think initially following the loss, it's really important to have that physical support, you know, and how to manage some of the physical changes that are going on with your body. And a lot of times that is the what people need most to begin with. Because, you know, it's much easier to talk about the physical changes, and people are comfortable about that, then the changes that are happening in your heart. So I think to create a safe space, to give them the opportunity to come forward and talk about it, is what we need to do. again, respecting the different cultural differences. And so, and there can be a wide variety of cultural differences. Some, for some cultures, it's [it's] important that you not talk about it. For other cultures, it's important that you not look into their eyes, right, that you keep your eyes down. But I don't always know all that. And so if I've ever done anything, I never want to do it to insult someone. It's because I don't know. So I think there has to be a little bit more education, to the healthcare providers on how to support different cultures as well. So and then again, for the family support, because it's not just the woman that's going through this miscarriage, it's also her partner, possibly her extended family if she has other children, as well and what does that mean as well for them as well. So I think the very first thing, because most people are dealing with a physical loss, you know, the bleeding, the you know, that type of thing before they can begin to hear, and then start to heal some of that emotional loss. So I think we need to improve that and then say, you know, here is some of the emotional support that we can offer here as well.

Mehrnoush: Will women come back for receiving emotional support later on?

Patti: I don't know, sometimes No, like with early pregnancy loss program, they do follow them. You know, if they've been referred there, then we follow them for the physical aspect of the miscarriage, but they also do a check in on their emotional support. And then if they need some more emotional support, then they'll refer to myself or there's other agencies or resources in the community as well, too. So is it 100%? For every woman? No, unfortunately. But it's [it's] a hopefully at least offered to them.

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Mehrnoush: How an application be useful to women who have experienced a miscarriage?

Patti: an application that you're trying to develop?

Mehrnoush: Yeah

Patti: I think that would be give a little bit of safety, that women can fill it out when they are ready to fill it out, that they're not fit. So again, some of that physical healing has started to happen, then they have a safety of being able to on their timeframe, be able to fill out that application, I think the application very possibly, would be able to be adjusted, as you know, with where ever any gaps are identified. And I think, again, it can be translated into their language if necessary, you know, because many immigrant women will have a translator app on their phone or, or anything, or maybe a family member, that can translate for them, too. So there is some less chance of misunderstanding of some of the things so I think an application would be really beneficial for anybody that is from a different culture and doesn't speak English as their first language for sure.

Mehrnoush: except this feature that you're talking about, other features should be different for different people from different cultures? is there any feature other than language that should be designed based on each specific culture in mind? For example, it should be different from for different religious or different people from different cultural backgrounds?

Patti: Well, language definitely comes to my mind, but I think very much different cultures will have different views on you know, when does that become a baby? Is it a time of conception? Or is it a time of delivery? And what happens to you know, the baby afterwards does it in their, in their beliefs, that doesn't have a soul? Does it go to heaven does it need to be buried? Does it need, you know, and that is very, very unique to each culture and each person as well. And to be able to respect that because for some people, the ultimate symbol is [is] holding that little body and being able to say goodbye. For other people, it's or faiths or cultures, it could be that well, that's just a shell, there's their soul or, or that, you know, they've already gone to heaven, or they've already gone to that, that higher power. And so to be able to respect that as well. For some cultures, it's really important that the body be buried within 24 hours. And sometimes there's rituals that are involved around that. And so to be open to that, I mean, some, some faith some cultures only requested the little body be wrapped in white, because of that sense of purity. And so I think that's something that we can definitely improve on in the hospital. So I'm always asking for white blankets and asking them to be kept specifically for our families that were that is important. And other cultures, it's really important that they be dressed in a very Fancy outfit because that is the outfit that they are going to, when they meet them. When they go to heaven or to the other side, that's the offer that they're going to meet their parents in. So, again, everybody needs to teach us what is right for them. And just because they're from a certain culture doesn't mean that that's what they want to follow. As an example, I have that I had a woman that was from the Islamic faith, and the Iman had come to pick up the baby to take to the, to the on my mind is just crumbling. Which he did the mosque, that's really interesting. But she wasn't ready to say goodbye to her baby yet. And Iman was literally pounding on the door saying, we need to take the baby now we need to take the baby now. But she needed to have more time with her baby. And so that was one time where I met the mom where she needed not the Iman what he needed. And I asked the staff to hold off on the paperwork to make an excuse that we didn't have a signature or something because we can't release babies without the proper signatures, because that was able to buy the mom a couple more hours. So yeah. So I mean, that's one very specific example that I can think of, of kind of going against the culture but meeting the woman where, what her needs were.

Mehrnoush: When women are using this application, they should receive unique information?

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Patti: Yeah, well, hopefully. Because again, many cultures are many young couples, young parents, they've never had death in their family before, or you know, so they just know from extended family, what you're supposed to do in depth. But many people will say, I've never buried anybody, I don't know what I'm supposed to do. And so then they rely on their elders. Because to give them some of that guidance. And so that can end up being very tricky as well, too. And sometimes, because we're such a diverse culture, we don't always have our elders around us. And so you're trying to reach family in that from another country and, and asking, What do I do? And then how do we manage it here in Canada. So it's, it is a beautiful dance. And so just hopefully, that we can make meet those families and try and make it the best as possible. Some families, it's really important, like for some of our Aboriginal families, it's really important that they transport the baby themselves doesn't matter what the gestation is, to the [the] reserve or anything like that. So sometimes we have to go through some hoops. But there's also some regulations that we need to have. some legal requirements. And so sometimes that can get confusing as well, for families too. it's confusing for everybody at the hospital. So if you're an immigrant or not. So, you know, we always have a vision, like the perfect vision is we never would meet these families, because these families wouldn't have had a loss. But then the vision is that it would all go very smoothly, but sometimes with waiting for a cultural leader to come and do a blessing, there may be a time thing or trying to get paperwork signed or anything like that. Those are all some of the barriers that we have at the hospital that aren't always within our control as well. So because I've had a family that, you know, they're ready to go, they they're all packed, but we don't have a doctor's signature, so we can't release things or if they want an autopsy done, because that can still be done on a later miscarriage. That can't always be done right now, it might have to wait until the next day. And so you know, what does that mean? So some of those are the barriers that we run into as well.

Mehrnoush: Okay, great. And when women come to your support group, in that stage, what they need most, and what resources do you have for them? I remember you talking about some resources that you ed together. Once we talked about some tech services and stuff like this, so what resources doing effort?

Patti: I think it's the emotional support the peer support, the feeling of that they're not alone, that other women have gone through this, and that it's not going to be as heavy and as sad, and as devastating as it is in the moment and you will still have moments of that. But sometimes it's that reality of seeing other women that are a little bit further along in their journey to know that it's not always going to be that sad. And then sometimes How do you continue to have a relationship with this baby, even though the baby has passed and how you continue to be this little one's Mom, and your partner continues to be the little ones dad, and how that relationship continues on. And one of the [the] things is, is by having a safe place to be able to talk about them. to be able to honor them. And you know, sometimes that ritual or that ceremony, when there are no words to explain what you're feeling, sometimes a ritual or ceremony can be really helpful as well. You know, people will light a candle at certain times, or they will, you know, write a letter or you know, even on anniversary dates, whether it's a due date, or an anniversary date to have something to acknowledge this baby. You know, like in the Japanese culture, having those little jujitsu statues. I don't know if you know, those are beautiful. And those are all for miscarried babies. And I have not been to Japan. But I've seen pictures of the, the gardens of that, and what a beautiful way of honoring. And I know that sometimes they go back and they [they] redress it, and especially on an anniversary date. So there's a beautiful example of how that relationship continues on.

Mehrnoush: And is there any difference for women who have other children compared to women who have no children, when they go through a miscarriage, as it harder for any of them or not?

Patti: I would say that it's different. Because again, when you've had other children, when you got pregnant, and then you had a healthy baby, that's going to be your perspective. So of course, getting pregnant again, you're going to assume your perspective is that everything will be healthy again. And so

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when it happens it [it] is difficult, but a lot of times friends in society say well, why are you sad? You have two healthy children at home? Well, yes, you have two healthy children at home, but you're still missing the child that you've just lost. If it's your first pregnancy, then there's always that you don't have a perspective of having a healthy child at home. So there's that perspective of pregnancy equals to this sadness. And so it I think, every subsequent pregnancy, there will be that loss of innocence, that fear that this might happen again, I think it is, I won't say better, but maybe softer or different, when you've already had healthy children to know that if you choose to have it again, that this can happen. But if you don't have that perspective of having a healthy child at home, it changes things a little bit as well, too.

Patti: Yeah, so yeah, for the supports. There's, I mean, there's the support groups, there's a lot of lovely forums online that they can connect with. There is even some of that creative support. There's some beautiful miscarriage colouring books, there is different songs, because a lot of people find healing in songs, in artwork. There's different memorial services throughout the year, like on September 23, the baby steps walked remember, is going to happen so people can come and honor their baby that way. And so there's another woman I know that does healing through grief healing through art. So she has their art classes, but they're specifically for scaffold that are grieving, yet. Some of them are miscarriages, some of them are just pregnancy loss. She's [She's] tried different things. She actually had, she didn't get the funding, but she was going to do an art show that was all around pregnancy loss. And so there's a few different things. So I think sometimes our logical side of the brain is trying to make sense of it. If we give permission to our creative side of the brain, it can balance things out a little bit too. There's also a lot of healing that can be done in connecting with nature. I find many women find either the mountains or the ocean, like water or, or the mountains can be very healing. So again, trying to find that exercise can be really important and these are not to forget about it or push it aside. It's just to give again, that very sometimes overworked logical side of our brain a bit of a break, as well.

Mehrnoush: Are they offering physical support too?

Patti: Well, some of them are physical, because again, when you have the exercise that's going to help that physical healing as well. And the endorphins in your brain is going to help with that and some of that emotional side. Again, I just find that most women can be find it very, very lonely. And so if we give them that safe place to talk about it, to express it to say, you know, I'm thinking of planting, you know, something in my garden to represent my baby. One of the things that we can sometimes have in our little Memory Box that we have for people is we put some forget me not seeds so they can plant that, or we have a little flameless candle that they can light on dark days. And so again, giving them some suggestions to see what kind of speaks for you. We have another family that donates this lovely little support, early loss support bag, and in there, there's a certificate for butterfly. So you can take this or certificate and pick up your butterfly and have another ritual of releasing that butterfly. Now that's not going to fit for everybody. But it is a beautiful way of saying that, you know, like butterflies, the way I look at it is that butterflies, we release them, and they're gone. But like her babies, they never ever truly gone because we always see butterflies might not be the same butterfly, but symbolically it represents the fact that babies are still with us.

I find a lot of people will wear jewelry, that will represent their babies. Maybe it's a little charm or, or something that they can wear. Some people will get tattoos that represent their babies as well, because for some cultures, tattoos are a very important piece. For some cultures, tattoos isn't what's important. So, again, to give them options to give them ideas to give them a starting point to think of things. And I always say you'll know, you may not know what's right, but you'll know what's wrong. Right? So some of these suggestions go Nope, nope, that doesn't fit for me. And that's okay. Or someone else you might hear and go oh, maybe, maybe that's something I would like to try.

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Mehrnoush: Do you have any additional comments that you feel are important to mention?

Patti: again, I think what would be really helpful is to have like that multicultural broker type feature where women that have possibly been through a miscarriage, and then to mentor women that are going through a miscarriage. So from the different cultures and stuff like that, so that they can teach us also what would be important. I think that would be a very important piece, because I don't think we should ever assume what women need. I mean, we can I have general ideas what women have taught me, but I don't want to ever assume I always want them to teach me what they need. And if they don't, if I don't know what I want to be able to research it as well. I think the other thing that would be really important is to acknowledge that to their partners, whether they are involved with this or whether they're not involved with this as well too, because I think often the [the] men are forgotten about, and to see what they can add to it because again, that culturally, I think that can have a big, you know, if you come from a culture that maybe it's very patriarchal or something like that, and a man tells you what you were expected to do. And again, if that doesn't fit, I just really think that women supporting women is so important in cross culturally as well. And we may not know exactly what that woman needs, but we can still be empathetic. And we can listen. And we can learn.

## Cyndi Mcload

*Adult Grief & Loss Services Manager at Abbotsford Hospice Society*

Mehrnoush: How long have you been practicing as a social worker?

Cyndi: I've worked with women for a long time. But in the work that I do now, I'm in my third year.

Mehrnoush: How much experience do you have working with women who have had a miscarriage?

Cyndi: It's been more of a focus in the last three years.

Mehrnoush: Where have you found that women get the information they need from?

Cyndi: My experiences is women aren't sure where to go to find the information. And that's part of the reason that they come here.

Mehrnoush: Who do you think women seek information from them?

Cyndi: I would say probably it's online information.

Mehrnoush: And do you think that it's reliable information?

Cyndi: I think some of it can be, but it's hard to discern. And that's, that's a big part of the challenge for clients.

Mehrnoush: How women can make sure what they find online is accurate?

Cyndi: Part of that is very individual, right? Every circumstance is different. Some individuals are more astute at being able to discern fact versus opinion. Some women have had great support from the medical system, and others not. And so that impacts what they're seeking and searching for as well. And can definitely influence what they're finding. what they're relying on. And so somebody who's been less supported, I think, would have run out a greater chance of believing information that may not be factual.

Mehrnoush: How do you evaluate the care women receive?

Cyndi: When people come to see me because my focus is bereavement grief and loss, they will often share what the experience was. And sometimes the women will share that they felt very supported, that the doctor has been good and explain things to them. And others feel like they were just a cog in the wheel of the healthcare system. And there wasn't any patient centred focus around helping them to better understand. they were just left to go through the process and Flounder on their own.

Mehrnoush: Could you explain more about their experience?

Cyndi: I think it boils down to person centred care versus what feels almost like robotic or very clinical support. And I think there's a real need. And there's a real need for a personal aspect to all of this. Some people, some women have expressed that they feel like they were brushed off that, oh, don't worry about it, get over it, you'll be fine. But that's not terribly helpful.

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Some, some women feel traumatized, but it also depends on their personal background, their history, what's going on in their lives, Right. So that impacts as well. And understand that the system doesn't necessarily have the capacity to be able to meet women where they are, to be able to unpack some of previous trauma, personal history, that kind of thing. However, I think the system could be more supportive, even by providing a resource list to women. So that they would have, have some information and know that when they were looking up different websites that these had been vetted. And they could trust the information that was there to know the resources. There's still a lot of oh, well, you'll get pregnant again, don't worry about it. Yeah. Just so they feel very alone in the journey.

Mehrnoush: Is there any difference if the women experiencing a miscarriage has other children?

Cyndi: I Think it's loss. Like it's loss for both, For sure. I think sometimes the impact can be different depending on if this a third or fourth miscarriage versus a first miscarriage. Emotions go, run, gonna say run deeper, and it's just there's different plus magnitude of loss, right? Like, will I ever get pregnant, whereas after a first, there might be more hope that the next pregnancy will be viable. So those kinds of things.

I don't know that it's different intensity of the experience, I'm not sure it's a whole lot different if someone has children or does not have children. I've seen it impact both women equally or as gravely.

Mehrnoush: What barriers do women experience to reach their healthcare providers?

Cyndi: Well, in our province, it's not even simple necessarily to have a healthcare provider. If you do not have a physician, it's not easy to find a new physician. So that can be hard. It can feel very impersonal, and personable because you don't have a relationship with the people that are supporting you through this. And so then it can feel very clinical. It really depends on the individuals [who are] who you encounter along this path as to how well you may feel supported or not feel supported. Depends on how busy the hospital is, all of these factors, and we get that cognitively, but our heart has a hard time rationalizing and receiving that information.

Mehrnoush: Is there any specific barrier faced by women because they are immigrants?

Cyndi: I don't know that I can speak to that. Because again, most of the women that I've worked with are not immigrants. That's not something I am really aware of.

Mehrnoush: When women having a miscarriage, who are the first people women connect with for support?

Cyndi: So I have to understand that the women that come to me haven't necessarily felt supported in their families, in their communities. And that's why they're reaching out to the Hospice Society, because they need some support. And that, so I, I don't hear a whole lot about the great support, Prior to coming. I think if there were more support available, I would probably see fewer women who miscarried than I do.

Mehrnoush: How women find out about your organization?

Cyndi: They may find out from a healthcare provider, their own family physician, possibly a friend or family, or maybe they've had an experience with the Hospice Society previously, maybe they know somebody who has used our services previously. That's often how people find us.

I just again, more of the women who come for miscarriage reasons are here because they've not felt supported by their family or they don't feel free to have the conversation.

Because their experience has been very different than their husbands experience.

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It feels like potentially the husband has gone on with his life. He's, he's getting over things, are moving on. Whereas the [the] female is feeling less able to do that. The women that I have worked with miscarriages concerns feel often feels like their husband has been able to navigate this journey a little bit more so than they have. Not that they feel dismissed by their husband, but the intensity of the feeling. The impact of the feeling is [is] very different. It's the female's body who has begun to change. The hormone levels are changing all of these pieces. The husband knows that the wife is pregnant, but he hasn't had often hasn't had experience. Feeling the baby getting to know the baby in the same fashion but the female's body is already shifting and changing. I do think there's something in there.

Mehrnoush: what post procedure support women expect to receive but they don't receive after a miscarriage?

Cyndi: I think it's very hard for women that are basically told to go home and allow their body to do what their body's going to do. I think there's a good bit of fear wrapped up in that procedure. There's a lot of unknowing. I think there's a lot of isolation, loneliness in all of that. And I think that's where a lot of, a lot of the concern the [the] after impact begins, right? It's okay, you'll be fine. You're miscarrying, go home, but your body do what it's going to do. And I think sometimes when the body doesn't do what the healthcare providers think it's going to do; women can be dismissed. And sometimes it's two or three times they go back before something else actually happens for them. So I, again, the capacity of the system to be able to hold somebody's hand through this process is limited. But if we took the time to sit down and truly explain, okay, we are sending you home, because this is, this is what we anticipate, this is what we feel from experience works best or explain. But if this or this happens, then you need to come back or I think if there was more information given, if the time was taken up front, I think it would comfort women, and there would be less fear. And potentially a different outcome on the other side of things, if we could provide the conversation and provide some resources.

Mehrnoush: what support groups are available for women, and how often they run.

Cyndi: So we don't have a miscarriage support group. And in fact, when we've attempted to hold evenings totally focused on miscarriage, infant loss, that kind of thing, we get very little response. And so I think there's stigma, I think there's a lot of pieces around it.

There are groups available. One of the positives from COVID, is the groups are available, usually online, as you and I are meeting. And that is a real positive, I think there's something to be said about being in the comfort of your own home. I think that helps people to show up, in some ways better, help others to be able to hide as well as opposed to being present in a group. So pros and cons, right? But it'll, it means you have access to supports that you might not have had pre COVID. And so there's definitely positive from that perspective. And so it's usually what I do is I put resource list together for women who come in and provide them with that resource and know of a few groups and will encourage them to reach out.

Mehrnoush: May I have access to these resources?

Cyndi: I will send you an email.

Cyndi: Yeah, I just, I, you know why I've just found some different people on social media, that kind of thing that I think could be supportive. And we print off some articles, give some names of the resources centres available that offers support groups, that kind of thing.

Mehrnoush: Women prefer to have their cameras off or on in an online session?

Cyndi: it's really, very personal choice. I always attempt to encourage people to turn their cameras on. Especially when we're doing support group, because I want to be able to attempt to read body language

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and sort of recognize if somebody has been triggered, or some can do some follow up. Online you don't get to read the energy in the same fashion, which can definitely. So often, what I've done a group online, I like to have another person present as well. So one can sort of be attempting to read the room and watching behavior while one is facilitating, because it's important to be present, right? And when you're attempting to navigate 10 or 12 people and the chatbox and facility. It doesn't, I don't want people to feel as though they're not important. And the focus is not on them.

Mehrnoush: How can we support women better?

Cyndi: I mean, I think that's a very individual, but I think the gift of presence is really important. I think it's, again, I think it's important to have more than one person, sort of leading, like a co facilitator or facilitator kind of scenario, with different opportunities. I mean, I think breakout rooms can be incredibly effective. Because you feel like you have some privacy, and you can share a story, that kind of thing. So I think that breakout rooms are really important. Maybe a piece as you establish a, a chat platform for the participants in that group. So that they can come together and have that piece available. Offer them that opportunity. We know ahead of time, who is prepared to join or share whatever, or at least plant the seeds for that information. And as the group has been together for two or three sessions, and you can put the ask out, is this something that you would like to [to] have included in your support?

Mehrnoush: Regarding the application, how can an application be useful to women who have experienced a miscarriage?

Cyndi: So are you just speaking sort of to like an intake application? What are you?

Mehrnoush: A mobile health application

Cyndi: So the supports that I have available under my roof are limited, but one of the pieces that we have is one to one companionship, and that can be incredibly supportive. And we don't have counselors available, but I know of counselors or where people can go to find counselors. I will sometimes offer the support. Ask them if they would like some support around finding a counsellor because I'm happy to sort of walk alongside until they're able to secure the support that they think they're looking for. That kind of thing. I really think asking them what they're looking for is most helpful because we, we may have not verbalized. But we know deep inside, what it is we are seeking. And I think if you have some option, are you seeking in person support? are you seeking, are you open to online support? Do you want telephone support? Are you seeking support from a counselor? I know that they don't know is it going to be long term, but I think if you sort of put a finite, if you do a group, and the group is eight weeks, six, eight weeks long, it's an opportunity for conversation, to come together to learn mutual aid support, that kind of thing. If you do a drop in group, one of the challenges with drop in group is everybody's at different stages that one of the beauties of drop in group is everybody's at different stages. What I think might work for one won't be what the next person is seeking. So that's always a conversation I have. So what [what] support do you think you might be looking for? What like that support look like? What do you think would be helpful, or bring you comfort?

Mehrnoush: How can I know what women need without having a conversation with them?

Cyndi: I don't know the answer to that. Because I [I] do ask my clients what they think they're seeking.

Mehrnoush: What are the answers?

Cyndi: Often they don't know what they're seeking. many times, just having the opportunity to come and have an hour to have conversation. But there are a lot of air over their balloon. And they feel better. One

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of the big pieces that I hear from women is I feel like it's only a miscarriage. So I don't feel like I'm deserving of time and energy spent by a counselor or whatever. But again, we don't know what's underneath in their history, right? I don't want to support them to compartmentalize and, and put this away for it to come tumbling out down the road. I think one of the things that women really need is to know that wherever they're at, it's okay. If they're having a hard time, it's okay. It's reality, it's their reality, and they are allowed to reach out for help and support. A miscarriage isn't a lesser loss than losing a child who was alive. It's still a loss of dreams, hopes, wishes of a child. Right. So I think, I think that they need to be reassured that it's, it's perfectly okay for them to be reaching out for help and support.

Cyndi: I think your language is going to be really important. For sure. Can you even just state that their sharing is really important in supporting them along their journey? Yeah, I don't know, like I said, I tend to ask, what do you think support life for yourself? What do you think would be of benefit? You can ask something along those lines on your form.

Mehnroush: What do you think about peer support?

Cyndi: So some do and some are not. group oriented are not looking to have connection with others. And I think some of that comes from fear, again. But I do think there's true value in mutual aid, mutual support, in learning that you're not the only one who's had this experience. Knowing that others are struggling, as well, can make it a little bit easier for them.

Mehnroush: Do you have any additional comments that you feel are important to mention?

Cyndi: Not that I can think of, I just, I really think it's important just to meet people where they are. to listen, actually to listen to learn. Because they will share. I think it's important for people to know that all the information is held in confidence, those kinds of things, that they're not obligated to answer all the questions. That may be a reason why they're reaching out to you for support, right? Because they don't know the answers to the question. That's okay. even the question of okay, so when [when] do we start to investigate? If there, is there a problem or not? Was this just a random spontaneous abortion of a pregnancy? Or should we be looking to see, is there an issue that's preventing me from carrying a viable pregnancy? Right? I even those kinds of questions. Because they don't know. That's, that's a piece that I often hear from women as well.

Mehnroush: Could you tell me more about this?

Cyndi: if you've had one miscarriage, you're kind of left on your own, so to speak. But if it's a third or fourth, it's like, okay, so I want some answers. How do I go about getting the answers? When do we start to intervene? What does that look like? Who do I talk to? all of these kinds of pieces. even to have the reassurance to know that this number of pregnancies end up non viable. But this percentage of people go on to have a viable pregnancy, this percentage of people may go on to have non viable pregnancies and investigation needs to happen to see, to determine what the cause, or what the reason behind the non viable pregnancy is, that kind of thing. Does that make sense?

Mehnroush: Yes. Earlier you mentioned phone support. How do you evaluate it?

Cyndi: It's sort of lowest on my list. Because you really need to listen well. you need to be able to be sort of know, you need to be able to listen to what's being shared and offered. But you also need to listen, to tone and to spacing and to try to discern some of the energy behind what's being shared and what not, so it would be hard. But it is better than nothing. And my suspicion is, there are people in our country that could benefit from what you're attempting to do, because they have very limited access to in person, or even internet, that kind of thing. So, phone support is important. I think we need to take in to

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consideration the demographic and so how do we meet the needs, and the needs for my community may be very different than the needs for your community, or those kinds of things? What happens to the women that have to travel quite a distance to a hospital? And they're literally left on their own to navigate on. It's very different than somebody who lives in an urban environment.

Mehrnoush: could you explain more about this?

Cyndi: I mean, I think it depends on the medical services that are available, right? I happen to live in an area that is really hard by physician retired, prior to COVID. It's very challenging to find a physician. Maybe some of what could be on your resources is even some conversation around how to prepare your body for a viable pregnancy. Nutritional aspects stress, sleep, all of the pieces that we know, that we brush away, but the healthier we are, the more likely our body is able to support us, no matter what we're doing, right? If we're incredibly stressed, I'm going to guess that that's going to have a big impact on the viability of a pregnancy or not, right, because it has a huge impact on our body functions. Those kinds of even conversation around pieces like that. I think an information could be incredibly valuable. We live in a world where everything tends to happen very quickly and, and somewhat easily, right? And we just assume that women will get pregnant but that's not true. And I think some education around some of these pieces be important as well. Not to be a dark ominous, but to be real, to have access. I just, I have a bias in that I feel called I mean, it's been proven. Women's Health has not been studied in the same fashion that men's health. that's from the vein that I'm speaking, right. And I can imagine that it would be very hurtful to have a male doctor just sort of fresh off this experience. He is never going to know what this experience is, like, ever. You may know what it's like as a husband, but his body will never experience this experience. Right. And so to have some information, maybe to have a team of people that are available to reach out to, to have some chalk conversation with.

Mehrnoush: How do you think women will accept an application?

Cyndi: I think because we're talking a younger demographic, I think the likelihood is far greater, because they've grown up with phones, many of them, right. they use their phone for everything. So I think that there definitely is a strong likelihood that it would be received. What numbers? Again, that depends on them. But if it's something that we have apps for everything, why not have this information available at fingertips?

Mehrnoush: How can I make it more reliable for them?

Cyndi: That's the hard part, like how are you going to do the resources because it will have to be a general resource. Because you can't have the resources for every community. By the same token, some of the resources that I give to clients are not Canadian resources, like the UK, Australia. They tend to be ahead of us in a different kind of way. And so I pass that information along. And so there's beauty in that as well. Because we have access to things, you're [your] app can have access to, to those kinds of supports that 20 years ago, that wasn't an option. Go to a library and look an encyclopedia or take a book out. So I think there can be incredible value. But listing like, does your health authority have support group around this? Just your health authority have information around this? your community. These are the sort of the more typical places where you might find some support. These are some of the global supports. These are some of the national supports that are available.

Mehrnoush: Do you have any additional comments that you feel are important to mention

Cyndi: From everybody, it's hard to take that information, right? And put it to the side. Yes, like, okay, so I'll give you an example. My daughter in law was pregnant at the very early part of COVID. She woke up, it was her second pregnancy. she woke up in the middle of the night, and there was blood everywhere. And

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so they went to the hospital. my son was able to go in with her, then that were told that they would have to come back because she'd have to have an ultrasound, but you wouldn't be able to do that at this point in time. So they were sent home. you know, as soon as they got home, they got a phone call, she had to go back to the hospital. Between the time they first went to the hospital, and the time they returned, which was only a matter of a couple of hours My son was not allowed in the house with her. it shifted right. So here is this woman who knows, because most women know if there's bleeding, potential for viability is at risk, big time, right? So she now has to go into the hospital by herself. She has to have an ultrasound by herself. And she has to sit and wait for 45 minutes for the doctor to come and talk to her all by herself. Conversely, her partner has to sit outside the hospital, knowing that he's not allowed to be there to support her through all of this. What kind of trauma are we invoking upon? why some of these practices and procedures, right? That's not okay. And so those are the pieces Where a person-centred care. He was just in the hospital? Could he not come? And I understand it's pandemic. And it's a little bit emotional. But I, I look at that from my own family experience. But I take that into the bigger world, and what trauma has we invoked upon women who have experienced miscarriage in the last 20 months? Really, Do we make the partner sit in the waiting room and the female go through all of these pieces by themselves? Those are, we need to shift and change that in a different way.

Some compassion can make all the difference to what happens post miscarriage as well. Right, which then impacts the body if you're talking about attempting to become pregnant again, right. It's the stress and we need things to be optimal. But the system doesn't necessarily support that. Some of the pieces and the mechanisms, right. And I know, that's pandemic time. But we do that often, without really thinking about the consequence, because it's easier for the doctor, or it's less time consuming for the healthcare professional. Is it? because now we have somebody that we've maybe traumatized that we need to navigate? Whereas if we took that five minutes upfront, we wouldn't have to take the hours to go behind Or afterwards, right?

## Lori-Ann Huot

*Grief counsellor/ Program Coordinator at Angel Whispers Baby Loss Support Program*

Mehrnoush: How long have you been practicing as a social worker? How much experience do you have working with women who have miscarried?

Lori-Ann: I am not a social worker; I am a grief counsellor with all my education specific to grief. I completed my education 5 yrs ago but have been working with women who have experienced the loss of a baby to miscarriage for 19 yrs as I am a co-founder with the Angel Whispers Baby Loss Support Program that was founded in September 2002.

Mehrnoush: Where have you found that women get the information they need from? (healthcare provider, internet, friends, etc.)  
Is it reliable information? Why or why not?

Lori-Ann: I feel most women get information when they experience a miscarriage from Google, healthcare professionals, friends/family & referrals to the Early Pregnancy Loss Clinics in the Lois Hole Women's Hospital or the Grey Nuns Hospital.

Depending on the source they seek the information from will determine the reliability of the information. Sadly, there are many misconceptions about miscarriage loss and many people (including healthcare professionals) lack the compassion & understanding to best support women (and their partners) through their loss. I find the best support for women has come from the Early Pregnancy Loss Clinic (esp. at the Grey Nuns Hospital) who then refer women to our program for emotional support following their loss.

Mehrnoush: What barriers do women experience to reach their healthcare provider? (Language barrier, cultural differences, appointment wait times etc.)

Lori-Ann: I think currently one of the biggest barriers is Covid and the long wait times/inability to see physicians in person. I do think for women of different ethnicities that there may be additional challenges because of language barriers & cultural differences.

Mehrnoush: Are there any specific barriers faced by these women because they are immigrants?

Lori-Ann: I would think lack of familiarity (and therefore lack of confidence) with our healthcare systems and knowing where to turn for help would be a specific barrier faced by newcomers to Canada.

Mehrnoush: How are the women's experiences with healthcare different in Canada compared to their native country?

Lori-Ann: It would be hard for me to speak on this because I am unfamiliar with the specifics of healthcare in other countries.

Mehrnoush: Who are the first people women connect with for support and feel comfortable with?

Lori-Ann: I think the first people women experiencing miscarriage loss reach out to is family & friends.

Mehrnoush: What post-procedure support women expect to receive but don't receive after their experience?

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Lori-Ann: I think often women expect better support from family but because of cultural expectations and influences and misconceptions surrounding miscarriage loss, they don't receive the support they need from them.

Mehrnoush: What support groups are available? Can you tell me about them? (e.g., how often they run)

Lori-Ann: I run the Angel Whispers Baby Loss Support Program and we offer a specific miscarriage support group that runs monthly. This group is facilitated by other bereaved parents who have received support and are in a strong place in their own grief to be able to support others.

Mehrnoush: How can they be improved to be more supportive?

Lori-Ann: Currently our meetings are being held virtually because of Covid, we hope to have them return to in person meetings once it is safe to do so.

Mehrnoush: How did women who have experienced a miscarriage get the information they needed? (healthcare provider, internet, friends, etc.)

Lori-Ann: I do believe women access the internet for much of the information they seek (whether it be through google or social media miscarriage groups & forums), however they also speak to their healthcare practitioners, family & friends.

Mehrnoush: What supports are most important for a woman who experiences miscarriage to receive? (e.g., mental health services, information resources, family support)

Lori-Ann: I think the most important support comes from others that have experienced similar experiences.

Mehrnoush: How can an application be useful to women who have experienced a miscarriage? What features do you think would be most important for it to have?

Lori-Ann: Accurate information that acknowledges the emotional & mental health of a woman experiencing a miscarriage in addition to the physical health. Links to community supports along with a FAQ (frequently asked questions) section

Mehrnoush: Do you have any additional comments that you feel are important to mention?

Lori-Ann: Overall miscarriage loss is a disenfranchised loss resulting in women often feeling misunderstood and not supported in a way they need or deserve. There needs to be better supports overall from every area of our society starting with healthcare practitioners who understand the significance of a miscarriage loss and the impact a loss has on families. Love isn't determined by gestation, these families love these babies from the moment of conception and grieve for them. Families also grieve lost hopes & dreams of their future without their baby.

## Ammneh Azeim

*Director of user experience at Alberta Health Services*

Mehrnoush: Can you tell me about your current and previous professional experience?

Ammneh: Yeah, for sure. So I have been working in user centre design field since God like 16 years it's been, right. And I also lead user experience Edmonton Which is place where we put a yearly conference, bring thought leaders and a place where we have folks from a user-centred design background, or people who are not don't have that background come together and learn more, right? I have worked with public and private sector for the at least, before I joined AHS. So I've been with AHS for five and a half years as a digital experience lead. But before AHS as well, I've been working with various private and public sector. I've been engaged in a lot of government work as well as private sector and helping them improve their overall user experience for their digital products, as well as the services. So I also worked with Government of BC, where I was part of like improving their service experience, which is beyond just the digital experience. And here at AHS, my team and I are responsible for the digital experiences when it comes to any of our products, digital products, at Alberta Health Services. We are a small team. So we have to highly prioritize what where we get involved. So my team and I are responsible for research, understanding the problem domain, understanding who our specific audiences, how they approach, you know, seeking information, understand taking that information, and incorporating that as part of their overall well-being. And we then take that understanding. And we work with various stakeholders within our like experts coming from the medical field, technology experts who can develop that. We are almost like in the middle of that like where there's that patient or our staff or front end, our frontline healthcare workers, we reduce the gap between what they need between what our programs need and what IT can build. So and then we define a solution and design it, prototype it, we evaluate it, see if it's working a lot. And then we work with IT to make sure it's implemented. And also provide advice to any of the health products where AHS is partnering with Alberta Health. So I've tried to provide that expertise over there as well, though how they're taken is different. But yeah.

Mehrnoush: Have you ever design and mobile health application?

Ammneh: Yes. I was involved in our organization, Alberta health services rolled out an application called Connect Care. that was integrating many different other tools like 130 or so different applications together, right? And there is also a patient portal side of it, right? So my team and I, we worked on providing feedback and design feedback on that. It's like, out of off the shelf product, right? So we couldn't necessarily do too much. But we were able to still provide input on the look and feel of the application to make sure that patients when they are using it, it's very clear for them, what are the main actions they can do on the application. And then also, because there were two patient portals, like one by My health records, under the My Health Record umbrella. One is that government was putting out as my personal record, and then from AHS aside, my AHS Connect, right? So my team and I worked on trying to figure out the ways how we could basically reduce that confusion of two portals for Albertans. And also when people use my AHS Connect mobile app, right, what that experience will look like. So that's the part I worked on. Other mobile health applications, I don't know, I'll work on online COVID assessment that like so, when during pandemic, my team and I we came up with the idea of building an online assessment tool. And it's mobile friendly. It's access to always like, in a time of unknown and where Albertans were struggling for information that, I have sniffle does that mean I have COVID? What to do? Why do I need to get tested, it was chaos? So we put a tool together in three days. And then we shared it with various other jurisdictions, national and international. And then we've been working with our IT teams and other stakeholders where we expanded that online assessment tool and integrated it to our public health operations, for testing and getting the results back in Albertans hands. And the testing strategies have

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evolved since the day was launched till now, and has been evolving every day, and we've been keeping the tool up to date and ensuring that is still working for a board.

Mehrnoush: What are the differences between designing for an m- health and non m-health application?

Ammneh: Okay, that's a very good question. So designing for a health applications are anything we ever think of? let me give you an example of say, like apple, right? So Apple constantly comes up with new gestures and new interactions, right, which has a bit of a learnability. Right, and they take certain factors from again, gamification, you know, to be able to engage certain audience groups, right? That type of thing would not work for health mobile application. And the reason is that the how they use the context of the use for health applications, is a lot more critical compared to non-health. So the user would be stressed, they might need to use it and stress, if they're sick, they are like, their cognitive ability is different, right? And their information processing is different. So I think, a lot of times, we need to consider that they offer health applications, everything has to be following the lowest common denominator rule, where that okay, learnability, for certain other applications, we have a certain, threshold that they could go through, versus it has to require zero learnability. And it will have to match more and more to what people are already used to. So like I'm having understanding of the, I'll give you an example of that. Just a simple calendar. a calendar that you hold, and you can select your date of birth, right? So the idea is that currently, a lot of times a sales promotion technology like oh, well, everybody's using this calendar. widget, why they can. And however, the way my team and I have designed where has always been single, simple drop downs, right? Nothing fancy. Yes, a calendar looks amazing. It's beautiful. It is maybe modern. But for an older person who is trying to just find out, can I see my lab result right now, right? for them just to get through and figure out how this is going to work? They again, going back to that lowest common denominator, right? They might be used to their current calendar in some areas, but they're still required at that time that they may are accessing a health application. There are so many other factors of their health and cognitive ability that may have lowered that learnability, but further, right, so. So that's one of the things and I have to say struggles for me personally, to communicate or get buy in, from everyone around me to that, yes, we do want to modernize, but mind you, our audience group is not ready for that. Like we have to go where so if the world has gone from in terms of modernization and user interaction here, how, like, you have to pick that and go tested with your users like what are the most simplest interactions that we can take, right? So a lot more understanding of the cognitive ability of our users right? And ensuring things are as simple as possible is that's where what I would say big differences are between health and non-health.

Mehrnoush: Do you have a framework to use for your design process?

Ammneh: There are a lot of user-centred design frameworks, you know, I think the thing, the way you would think about user-centred design, and also design thinking is that instead of tools and processes, right, and you can, never kind of take it exactly the way it is. I'll take a look at what it like, I don't necessarily use like a very set Framework, to say, okay, we're always gonna have to follow, but the main framework that I do use of it in our team is understand define, solve, evaluate, which is a design thinking big buckets. And that's just so that we build behaviors and practices that we can jump into solution, without understanding the problem first, got to get comfortable the problem enough, and the people who are using it, understanding that, before we get into solution, and also getting comfortable with this iterative method, you know, that we can use design as a conversation where you put something together, you get feedback, understand requirements, and maybe you have to scratch the whole day and start all over again. So not necessarily cookie cutting into like, or trying to, like, you know, fit if it's something that is like doesn't fit. Use design in that way. And instead of having a waterfall where you have all your requirements, and then you're gonna go design and you have a quick evaluation now, it's like, has to be a conversational thing. I just give you an example. Recently, we're working. X reached out that okay, and again, it's, I know you're recording, and so maybe I shouldn't use the exact names like so scratch that.

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Mehrnoush: I can just delete that name.

Ammneh: Okay. Great. Awesome. So we were working towards an application were for by, like, you know, to help Albertans to submit a request, whether if they have some issues with their health records. And what happened was that the team was using that information, they had more requirements, and they came back, right. And they came back with some extensive requirements, right? Which wouldn't be good for the user, because they don't have again, going back to the cognitive ability of a person who is stressed. Now Okay, I've got to get my health record. It's not working, why is it just me? What's going on? Who should I talk to you? And we ask all these D Hill questions from them. And they're like, I don't know what it means, you know, because my new, they're just like, they're sitting there, but themselves trying to figure this out, right. And not everybody functions at the same technical capability. So for us, what we had to do is show them first through the design, that how complex it can look like, right? And then bring it down to a level where we needed to just like show them, okay, this is compromised, like, you need this information. We can collect it this way without really making the user work too hard, right? So we used design as a conversation, right? To show them the complexity and then change the scope, right? Because so again, when it comes to the framework, again, going back to understand, define, evaluate, right? It's always like that understanding piece of it, right? and our iteration, right, that we always need to work through. And I'm a believer, like you, if you talk to other people within this industry, maybe they give you [you] know, a book version of the framework and you know, go do this, this, this step that I'm familiar with it, but from to practicality, simpler, you make your principles, it's easier to follow. and easier to modify, because you're always going to have so many different ways, like problem statements coming to you, and each one needs a separate special treatment.

Mehrnoush: How do you think your work is different from other designers?

Ammneh: I think Okay, um, well, depends who the designers are, right? So if we're talking about user-centred design, designing routing is much different, like so I'm familiar with some of the work the digital innovation office does, or some other agencies and they follow a similar approach, right? I will say that my work is different from say, like, pure graphic designer, or up your web designer in the sense that they think they are responsible for a piece of work right? There, where the requirements and everything come to them that this is expected, we need, like they have a prop, they probably have this process that I'm explaining to you within their head as well. But they're not necessarily like for instance, advocating for it, they probably do some type of research, look around or find ask questions, right. But I think a user-centred designer, they tend to advocate for the fact that we need to do that user research, we need to understand your audience first, right? versus a graphic designer may ask you one question, Who is this for, but may not ask the details of what the behavior of your audiences, what their needs is, like, a graphic designer may ask you what information you want to show. But they won't ask the question that user-centred designer were asked that, why you want to show this information? How, how is this information collected right now? Why? Who's being collected for right? Who uses? What, what? Your audience how are they going to use this? For what step? What's next? How is it connected to the step after that, right? Those that's just the difference. And it can be really annoying for people because they don't know the difference. They still see us, I gave you this web page, this UI just design it. And I'm like, nope, we're gonna need to do a research we need to do understand if we were do a journey map, we're gonna build some prototypes, like. And I am lucky that I have been able to have throughout my career those people were already bought into that I never had to like, like, say, like, I am still advocating like, okay, that's a lie. And the guy you have to advocated every day even people who have already bought in. It's almost like a funny thing is like, it's almost like they sit back and like, there's something different. I just can't tell. So yeah, and for us just to be patient with those people, and it's like something to tell myself every day. Just be patient. Just be patient, please. Yeah. People are learning so.

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Mehrnoush: Okay, and what kind of research method do you use?

Ammneh: Okay. So, very good question. The research methods are qualitative and quantitative, right? Again, goes back to type of problem we're solving. Okay? If it's like, so when I like, if it's like a, hey, you know, what, we need you to redesign this whole page or this website, right? Or we need to create a tool for these specific people, right? And then I will say, Okay, I'm gonna do some qualitative analysis, right? qualitative, behavioral research, right? So I may do daily study, contextual interviews, Shadow someone at their job, do a bit of a journey mapping, you know, to, from the time within the scope of research, whatever the product is. So I give you examples of, for instance, if we are building a pathway to managerial cholesterol, right? So there's a patient or what are the different types of patients, someone already has a cholesterol, maybe someone who actually has a risk of getting cholesterol, right? And then there is the provider side, you know, like, you know, different types of doctors or healthcare workers who help these people. Okay. Now, we want to understand, so we'll do a bit of a more contextual interview for that with the patients. Okay, where did you find that information, what information you're looking for, who you talk to like, you know, Then we may sit down with the patients and do a wonderful journey mapping, right? So those are methods, right? So these are all behavior research, right? If it's an existing tool that already there, and we're redesigning it, then we more and more know how come quantitative data come into, right? So analytics, and you start that we are collecting, so and then we take merge both of those, and see, okay, this is qualitative information, we got qualitative data tells us a lot more about people's behavior, their approach, what's important to them, what motivates them, right? What what's a high priority, like a lot of prioritization of the information that what the main thing they want to get out of the tool, right? And quantitative data tells us that in current, whatever we have, what's working, what's not working, right. So and then, and then I made you say, like, Okay, if there's an existence, you, I'm gonna do a bit of a usability evaluation of it. Like watch people use the product, right? to see, and those give us a little bit more like tactical design elements, you know, combine that and then and then we go, Okay, well, x, y, z is the problem, right? So we need to make sure this problem is solved. And then from the behavioral and contextual interview and the journey mapping, okay, these were the important things for the users, they want to understand x. So this was a problem in the current solution. This is what the need of the user is. So I think this x was that this box could be done this way. Put a prototype together, take it back to the users with the new design information, see how we can use it. So. So that's one, but it's possible sometime that is how we have information hierarchy defined on a website, right? So it's like, maybe we have loss of resources for patients, right, that they need to find out in case of you're sorry, that the people, the pregnant lady is ready for the multiple and if they've gotten an abortion, or where they were, like, you know, different resources, right? So say, like, let's say you have, like, I don't know, 200 pages of information, right? How should you categorize it so people can find what they're looking for? Right? Then we may do card sort activity, right. And Card sort activity is like close or open source, you know, so you can understand how people are thinking this information, because if you get how they're thinking, then you will know how to build it, so it matches to their thinking, then I can put based on the cart, so I may put some high level, like no buckets and, and put my argument, and then I may do a tree testing, you know, so I'll ask them certain tasks that would be driven all of the research that we did previously, understanding, you know, pregnant woman with desires, or what information do we want to at different stages, we take some tasks say, Okay, well, at this stage, let's say you, you're pregnant in you got like, a spot, you know, What would you do, right, and then you will see what buckets, they're clicking to check in to make sure that that information is clear to them. So depending, again, going back to like, it's a big toolbox, right? And depending where, which stage of the product we are in, there's all this qualitative and quantitative study. So card sort and tree testing, you could make it qualitative, if you do one in person, or you can make it quantitative, you create a survey and send it out to a whole bunch of people.

Mehrnoush: How do you decide which features to add to your products?

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Ammneh: So in user-centred design method, the way you would do is that you could do divide by dollar, like so many different activities, right? So you create a list of features, and you ask your users, that put a, you only have \$3. And you can send spends on to all \$3 on one feature, or you can distribute it on three more. That way you will get what's the most important feature for the users, right? And it's a very important, important activity because what I see a lot of times in the field where we haven't fully driving a product management out of user-centred design methodology is that business keeps driving the features. It gets so overwhelmed with features that and that people like oh my god is so confusing to use it They, like smallest need the business had, like oh my god, let's add that. Smallest need the business like we never push back to the operation, you know, sometimes you got to deal with it, because we can overwhelm our users, right? So they keep going and keep going till it becomes like this humongous crazy team that no one gets it. Right. And, and that's one of the struggles I think people within my community is a user-centred design methodology have that we're still seeing in that design rule and on a product management role, right? Which makes it really hard to like a simplify your product, simplify your product and be able to control it right that more [more] features you add, is just going to cover and it was funny, like, you know, organizations, we sometimes we will look to us for advice, but then you could also be seen as the naysayer or the one who is not necessarily is the gatekeeper, not necessarily letting all the ideas go through. So, So it's a fine line.

Mehrnoush: How do you validate or test the usability of a design?

Ammneh: Usability evaluation in person usability, usability evaluations that I have done, always, I love those, because I feel like you get so much out of it, right? Like, there are, you know, online, like Usabilla, or something like there are tools where you can just send it and record. But I think a facilitated usability evaluation, you get way more out of it, than just sending it out to be caught a number of people, right? So making sure you have the right people first, right? People work really have interests and motivation to use your product, right? And just sitting and watching them, right? And learning and insights are unbelievable. There are people in our in our field who love usability knowledge, and the people who just cannot sit and go through it right. And I think you gain insights by sitting and actually going through it.

Mehrnoush: Have you ever been a part of a co-design session with stakeholders?

Ammneh: We do a lot of co-design sessions, right? So is there is a project right now, it's on hold because of COVID. Or every, we do a lot of workshops, right? So in person workshops, not because of COVID. That hasn't been happening much, right. But we used to do a lot of like credo basically. Okay, here's the user research, right? And then, and then we would sometimes have, like people who are representative public at the table, right? So when we are designing, okay, these are the problem statements. How do we want to solve this? So people will just provide input and [and] then there's so many different facilitation methods that I have used? Yeah, absolutely.

Mehrnoush: How do you think it's different to design with stakeholders compared to users, you know, in a co-design session?

Ammneh: Okay, so it's almost like dealing with politics when it comes to doing the stakeholders and users, right? So what I've done previously is that if it's just the stakeholders, right, it's going to be very biased, because it's all about what they think it right. So having users at those sessions where stakeholders are there like [like], you know, having a proper combination, or like a there are some stakeholders, there's some users, and then they can actually, so then stakeholder when they're giving ideas, right? And we get like feedback from user, right? They can hear it right there. Right? So that has been, it's been I've we've done some sessions where we make the stakeholders be there's a role play, they can also they are the user, and they're going to sit and they actually going to go through the product themselves. And that actually gets them build a lot empathy, like, you know, any empathy exercises that we can do. So people

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can see from a user's point of view for stakeholders is very important, right? So having users they're bringing in the research. But a lot of times stakeholders have a tendency of wanting to be the ones who define what the feature functions should be, right? So it's good that they have that ownership. But the important thing is how do we actually make them get that role playing going.

Mehrnoush: Are there any mobile application that you think provide good user experience?

Ammneh: okay. This is a really hard question. Because as a user experience consultant, you would never think of this they did is a best user experience ever. That doesn't happen. So how about not bad user experience. So our online assessment tool for COVID, right? Again, mind you, how you decide what's good or bad user experience is understanding who the user is, in what situation they're using it and how they're going through it. You can never say, Okay, this, this is a great application. And it's awesome. I can say that if I was the user of that application, and I had that motivation, and I went through it, right? Yeah. So for instance, you could tell us tell me maybe as your Amazon, if you use Amazon, right? So you can say, Okay, well, you know, what, Amazon has a really good user experience, because, because of why, then you have to ask that question from yourself, because you use Amazon for certain things. And it worked out very well. So I think there are lots of applications and things out there that have factors of good user experience incorporated in them. But I wouldn't say that there is one application, that's perfect, right? So for, I can, I can tell, for instance, in terms of like Amazon, having this veil where I could just like, change my account and have all my orders. And I guess that was as me as a user, it was perfect. It was really good, right? Or I could tell that medium, like, if you like the various articles and stuff like that, right? Because it shows you how long an article is, right? So that piece is a good user experience. Right? I can tell online COVID assessment tool. We had got some really good feedback on that, right? And I don't want to be the one who assesses that, because I built it right? And like it would be good for a user point of view to see okay, Was it good? No, no, like, we can tell that it has facilitated more than 4 million tests. So it's meeting the objective, right? We have got an anecdotal information, we have gotten usability information on it, and it has worked and it's working for people who are looking for that information. It's very clear to them, because they don't need to, they don't like it, they can answer question and gives them exact answer and let them test them. Right. But we also know there are things in there that we can improve too, so. Yeah. So I don't know how if how do I answer that? Maybe my own standard like I, I would never want to ever Okay, okay, Netflix has a really good user experience. All right, yeah.

Mehrnoush: Why do you think it has a good user experience?

Ammneh: So I think it has good user experience because especially again, let me let me tell you again, my opinion based on my usage of Netflix over time has changed right? So I like that it can it can I can skip like you know, the first. I like that on the phone, I can minimize it, but it still keeps like a small window and I can multitask now, right? Like that, it shows me based on my like, you know, need more or the different views, all right. So, we call this like, almost like comparative analysis, right? So when we are always solving or trying to solve a problem, we see okay, what are the different products? What are the things we're doing? How much of that can align to the need we're trying to solve? Right? So trying to build connections to that.

Mehrnoush: what can be improved?

Ammneh: Well, okay, we'll go talking about Netflix what can be improved. I think the algorithm can improve a bit better, you know? Not always. Okay, so here's the other thing. When it comes to user experience is not about the interaction always. it's about also content {and use} and then also context as well. Right? So the problem that with Netflix right now is that it doesn't have a lot of different types of content, right? Which they can absolutely improve on. Okay.

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Mehrnoush: Have you ever designed a digital solution specifically for women?

Ammneh: A woman health portal, which hasn't been launched. Well, we just had some conversations around, right. So we've been working with different organizations, like our foundations and hospitals, and [we're] our health units are specifically dedicated to women's health, right? So we were responsible to actually start putting together a bit of a strategy and some concepts around just how to promote information related to woman health, right. But we just had like a kickoff and some, but we haven't necessarily gone through it. But [I] the website, and one of the digital sites for AHS, my health Alberta, there is a woman health section of it. And I'm not proud of it. Like it was just before me that we have put that together. Right. But I haven't specifically built anything just for a woman in that sense. Yeah, no.

Mehrnoush: How do you think designing from women is different?

Ammneh: I think, if you so, it's very interesting question. Because if you think about like different personas, who, for a woman can have different personas in terms of how they seek and look for information, right? So they are women who are like very thorough. I wanted for me every they have like very well organized because they have like big families and they need to get everything sorted. Right. So they're very detail. They have a bit of a process and how things will go. They will have folders, they're super organized, and there will be woman. So like one information right at the tip of their hands, you know. they don't have the time. They're not thorough, but they're looking for information right there and, then right? so there is always going to be different personas with a woman and also women are good at multitasking. Right? And [and] they have this ability that they always have like multiple things happening around them, right, and they can manage at ease much easier, say like, the other groups, right? But so I think with [with] women, you have to, anything you create consider it needs to consider the details very well. Right. So they can easily pick it apart things that they can trust, you know, because it's hard to get woman's trust in an applications. Especially educated woman, you know, like the source of the information, right? They are community builders; they crave the relationships or they are very good at building relationships and friendships right? So having that opportunity where you can share and how build that community and learn from each other. Woman are champions in that right? so [that] considering that stuff, right but again, at the end of the like I'm talking about it because I'm a woman myself but always good to go back and just specifically research it from that angle.

Mehrnoush: What about immigrants? have you ever been involved in designing a digital solution specifically for immigrants?

Ammneh: So like I have, I can't remember Okay, what did we do? Oh my god, I was very long time ago not at AHS. So the AHS, for us, everything has been more like okay, considering ESL population right? Around immigration, it wasn't just immigration but it was like people who are coming new to so we needed to, it was with Alberta education. I can remember is like you know, understanding if you come if you're if you come in new to Canada, what the [process] education process is, right? So, and it was for also with Edmonton school board. And that's what we were so just, it wasn't just specific, but just anybody who's coming to Canada new understanding, making sure that they understand what the process is, right, and we have to interview those people see how they have gotten the information, who they usually go to, to find that information, right? What information they look for, right, so that we can have a proper hierarchy. Okay, what is exactly they're looking for. But that was, that was a long time ago. Oh, my God, I was like, 10 years.

Mehrnoush: How do you think designing for immigrants is difference?

Ammneh: I think we need to be, so there, people are going to be coming from different cultures, right. And as you come from different cultures, trying to help them feel at home is very important, right? People

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who are new immigrants, they have that, like, they're, they're smart people usually. And they're trying to learn the new culture that they're in. And they're great learners, right? But then they also afraid that you know, because everything is new, right? Like, they just left their amazing life, and they are starting all over here. So just ensuring that our language, now they also have a language barrier barrier too, so ensuring that we have proper translations, right. And we write very clearly, right. And also not too wordy. We can have like many, too many too many words and information that overwhelms them further, right. So I think for them, like going through plain language writing over and over again, that and then making clear set of steps, right, just so that they know they can whatever they need to do and how to follow. And also linking them to various resources that is specifically like put together for new immigrants. So if you need to talk to someone, like so I really like when on physicians, like you know, when we're looking for a new physician, it has a checkbox that preferred language, right? Like it just something like that is simple, but it will make a new immigrant who's looking for a physician feel so much better. Right? And also, I think, when we talking looking for the new immigrants, like, it can be just okay, one specific page just for them. it has to be integrated throughout all our systems. So, yeah, I think everybody's trying getting there slowly and slowly. And there's a lot more work to be done there.

Mehrnoush: Where do you go for UX design inspirations?

Ammneh: Oh God look around. I think everybody gets inspiration so many different ways, right? Reading a book or you listen to a podcast. And for me, inspiration comes in, like, you know, when I'm using a new app, or, or if I'm just walking around, sometimes driving and like, you know, the inspiration comes up. Like, why didn't this sign wasn't that clear that I needed to take a ride here? You see, the you were like a user-centred design person, you [you] feel like you have to, like you know, your loss of nails and you have a hammer. Inspirations are everywhere.

Ammneh: Oh, all the time. Yeah, like me, you know, when even with our own tools that we build, I use them and they'll be like, oh, yeah, so much, it could have been so much better. Right? And it's at a time you just have to keep your expectations super, you know, in check. So you're not necessarily, like you just have to see, okay, where where I can make a difference and where I can't, right. So and what the end goal is right? So things cannot always be perfect, so.

## Diana Campbell

*User experience engineer and storyteller at Alberta Blue Cross*

Mehrnoush: Can you tell me about your current and previous professional backgrounds?

Diana: Yeah, so pretty much I started my career as a graphic designer. So that's what I went to school for. Through the years, I've continued my education into more of web, behavioral economics, human factors, psychology, in terms of user, user experience, UI, best practices for that, as well as web development, project management, negotiation, and conflict resolution, that sort of thing. So then I was the web Communications Manager for a while. And then now in the digital experience department. And we primarily work, at least in my team, we primarily work on our surface web properties. So anything that anyone can find is what we work on and develop. In terms of that we do the content, we do the development, we do the user experience, the testing, the research, all of it, from concept to inception. So that's pretty much what we do. And other than that, we support that digital marketing. But I've done all things from working on the balloons that you do see at car dealerships all the way until, you know, brochures, advertising and website.

Mehrnoush: Have you ever designed an application or digital solution for health?

Diana: Yes. So we have worked, so one of the recent ones that we did work on is what we call Our Care Navigation. So in terms of navigating the health system within chronic disease management, and lifestyle management, and mental health support. So again, that's that's what we do all the time. We're in the healthcare space. So pretty much everything we do at some way, shape or form has to do with someone's health. Whether that be purchasing a health plan, because you know, we often don't get those health benefits one on one classes in school, to know what we should buy, what we need, what to consider in the future. Because we never really, we don't have a crystal ball to tell us when we're going to be unhealthier when something happens, all the way until supporting people obviously, when they're in that more of a treatment perspective and what they need to do to support themselves, and then how we can support them. In addition to that, does that make sense?

Mehrnoush: Can you tell me more about Our Care Navigation.?

Diana: It is pretty much as an information application, just providing information to people because the one thing when you're in a stressful situation, like you've all of a sudden been diagnosed with diabetes, or you've had a miscarriage or an ectopic pregnancy, or whatever the case may be, you are in, you are stress. You are highly emotional, and humans are rational to begin with. So trying to go to Google and find something can be extremely overwhelming. There's a million resources out there and you don't know who to trust. So it was primarily around supporting both the free resources as well as the paid resources you can get to support yourself and navigate the system based on the condition and where you want to go. And yeah, that's [that's] pretty much pretty much it. It was information based, and really looking just to support people with the information that they can trust and the programs that will actually best support them.

Mehrnoush: what are the differences between designing for a health-related application, or non-health related application?

Diana: But my favorite way to talk about this and I'm sure my team would laugh at me, but we don't sell t shirts at Alberta Blue Cross. So it's not the same thing when you're dealing with someone's personal

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information, their health information. it's again, it's very personal to them, so you can't expect rational decision making, you can expect that people know what they're talking about. And then you have to deliver it in a way that they feel empowered, they're in control, because a lot of the other things are not, they're not in control. Or, you know what I mean. So it's, I wouldn't push things like high e commerce selling the same way that I would, if we were selling things like t shirts, because it has to be that consideration, it has to be their decision, it has to fit into their life, their [their] wallets, also, because those things all cost money, their time. But yeah, it's not the traditional experience that someone goes on, they're not coming here to look for fun videos on tax, they're coming here to look at card information on what they need to support themselves or their families. And again, the difference is, it's [it's] most decision making are emotional, but this one, they're in a much different capacity. So they're stressed, they're worried, they're anxious, and we need to make sure that that we don't add anything on top of that to make them feel stupid, or that they don't know what they're talking about, or they somehow done it to themselves. So there's a lot of health information, that's a lot of blaming you for the things that you came into. So we really try to make sure our language is more proactive, less in terms of the biases to say, you know, you ate too much sugar, so you got diabetes. That's not always the way it works. Sometimes genetics also just comes into play. So that's pretty much my opinion is we do have to consider the mental state and then where someone is, and in this case, they they're normally when they're looking for that kind of information, it's because of a life event. And those life events have either been happy, yes, there are times like that, but they're also usually more stress and worrisome. So we want to be there to support rather than bush. And then yeah, in language that is geared towards a grade three level to support things like new immigrants, because they obviously can't read the English or understand the English language quite the same way. Think about cross cultural content. So some things we talk about might mean something to a different language, or a different culture. And then from more of just there's no reason to talk in health language and legal jargon. If we can avoid it, you can still get the point across without putting a whole bunch of words that someone now has to go back to Google to try and understand what you're telling them in the first place. So that's my long winded about the difference between selling shirts.

Mehrnoush: What about methods or visuals?

Diana: Yeah. So a lot of times, it's a fine line. So, I, people often think of health as being skinny, and fit and young. And that's not the case. So just because you are fit doesn't necessarily mean you're healthy. Just because you know, someone's overweight, again, doesn't mean that they're unhealthy. And finding that balance between showing those things without people seeing like they're being marginalized, can often be a part of that. And then things like we don't want to, again, go back to diabetes, like a lot of just because you have diabetes doesn't mean you're all on glucose monitors. So we don't want to put them all over the place. And just anything where it feels like it's shaming in any way that you have to be really careful with the photos that you do choose or the colours that you use, creating different emotions, and the other how you layout the space. So there's enough white space for people to digest the content without feeling overwhelmed. All [all] of those things are, are different and have to take in consideration and yeah, the photo selection is or creative assets in general, you do have to walk that fine line of politics, socioeconomic class, culture, sizes of ageism, and make sure to find something that someone can connect with without feeling like they're being discounted.

Mehrnoush: Do you have a framework you use for your design process?

Diana: You know, I would like to say that we have a formalized process but we do not. We're working on it. It's more of a work in process. So there's guidelines to how we do things from just the steps you would take towards looking in the research considering who your users, personas less from a demographic perspective more from a needs perspective, because it doesn't really matter where they come from necessarily or who they are, it matters what their needs are. And then at the end of the day, we just work through a process of wireframes, then high fidelity prototypes before we get into the development, just

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so we can go through all that feedback and also minimize any unnecessary work on the code side. But, yeah.

Mehrnoush: How do you feel that your work is different from other designers?

Diana: So I think, for us, it is the consideration of our business. So again, it's different than most other companies where we have to look at regulations, we have to look at what we're doing from a business perspective, but also a legal perspective, more often than not. We look at, we tend to start even with our research with user testing, to understand biases with people with their health data first. With that, it's also difficult for us, because we are Alberta based. So we often have to try to find people in Alberta that we can use for that. So it is a little different than designers who can go, you know, even in the country not alone North America. So we do have those considerations that we have to think about. And then other [other] ways that we design, at least for us is always that consideration of our legacy systems to be honest. So what we can do and what we can't, and how we're going to take that health data, how we're going to protect it. So for things like we can't necessarily do the newest and greatest things, adding AI and machine learning or any of those, because we do hold a lot of personally identifiable information, there's a lot of things we have to keep within the province. So we often have to consider that. As well, as we really interesting, at least, again, at Blue Cross, we have, we don't actually own the brand, we licensed the brand. So we don't necessarily have the same control as other designers who are working for a corporation, that's all under one umbrella. So we have to follow trademark rules that's put out by the Canadian Association of Blue Cross plans agreed upon above all the blues, and then considered with BlueCross BlueShield of the US. So it's really interesting because we operate provincially, more like individual companies, but all coming together on the same brand. So there's, there's a really big complexity and our markets are much different. Also, for us, when we design we have really strong relationship with the government. So there's a lot of things we have to consider with the political environment and what they're doing in terms of our users. So there are things we want to do that we just can't, at times. But yeah, it's navigating a really complex equal system, in terms of how we can support people, because we serve companies, individuals, the government, and then the community at large. So how do you take all of those into consideration without offending anybody but supporting everyone? And then knowing that not everyone has the same feelings, perspective, class, everything and take that, take that into consideration. So it's really taking all Albertans and trying to bring them bring them together. So it can be quite complex. If that is fair.

Mehrnoush: what kind of research methods do you use?

Diana: The biggest thing that we're doing for us is, is user testing, surveys, that kind of thing where we get out and actually ask people. Outside of that sometimes we rely on our research department. I don't know what methods they're using, specifically. And then we obviously look at an environmental scan perspective, but nothing that anyone else is probably not doing or as mature as they are yet.

Mehrnoush: How do you decide what features your application needs?

Diana: So when we look at that we look at bringing the business purpose together with the users intent and desire. So at the end of the day, there may be a really cool feature that we want to add. But it won't serve the users' needs in the end, and we do confirm that with them. Would you like this? Would you not? confirm that with our business. Sometimes, sometimes time and costs do come into that. So we look at it from a minimum viable product perspective. What we can get out the fastest iterate on. So sometimes, those features are just roadmaps through multiple phases, rather than a waterfall project perspective. But the features are primarily looking to be customer centric. So what did they need, and what's going to support them? And if it's a feature just for the sake of adding a feature, we're not going to put it on.

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Mehrnoush: Is it different when you're designing for health?

Diana: I do think it is. I do [I do, I do] think features are dependent on purpose. So for us, it has to be very targeted, you have to get them the information. We know people are going to abandon. Also right or wrong, I think that we need to have more focus on universal design and accessibility. So a lot of times those features put up barriers, where if you had a target market that really didn't necessarily ever serve someone because you're [selling high] selling high end, six \$600,000 purses, you probably don't need to care so much. And you just want to put a bunch of features that are going to get them to buy that bag, where we really have to be accessible to all so if that feature is not going to do something at the end of the day for the user, then we're not going to add it. And it has to have a direct purpose, not just necessarily a wow factor. It's more about the simplification of a process and a simplification of the site rather than adding a bunch of features, if that makes sense. Yeah. So it's a very broad spectrum. But yeah, I do think there's a difference between selling health data and a birth index.

Mehrnoush: How do you validate or test the usability of the design?

Diana: So right now we are using [usertesting.com](https://www.usertesting.com). So that we can go out there. We also work with our CX department to get out and actually survey our customers. [Don't know why my alignment like there.17;49] But yeah, we do use them to look at our actual current customers, then we look outside of that into obviously different industries and different users, and that user testing, and we are working towards building essentially a panel for accessible design, and more of that broad spectrum needs perspective. So if we can get someone in there who's using a keyboard versus a joystick, versus all the other kinds of assistive technology as well as cognitive disabilities, those types of things, and we're, we're working on that, but that is harder for us to get. And that will be part of our panel as well, to go out outside of our walls and figure out, you know, if these people are not customers, why aren't they customers? And if they are, is this something they actually need or want.

Mehrnoush: Has the user testing process changed because of COVID?

Diana: So for us, the process hasn't really changed. We were focusing on digital first before anyways, so and then. But I guess here's the thing. So the process hasn't changed based on where we were at the time, as well as our company. But I do feel like, I would like to be able to find a way to go back in person testing, at some point to see how a user we can observe from a different perspective when looking at that, but at the end of the day, not specifically we were on this path before anyways. So I didn't see a huge impact to what we were doing. If that's fair.

Mehrnoush: Have you ever been a part of a co-design session with stakeholders?

Diana: Yeah. So we, So whether I was part of it or leading it?

Mehrnoush: Both if possible.

Diana: So co-designing really using design thinking methods tend to be. So going about that more, yeah, with our stakeholders tends to be getting our stakeholders. let's go back. our stakeholders can be very fast. Have very, very, very, very different expertise. And then we tend to have a loss of sense at Alberta Blue Cross. So we can go into a project with 75 plus stakeholders, where we're trying to come up with a vision for a product that can be quite arduous. and managing that from more of a project management perspective, as well as focusing on the problem at hand, and when [when] we get the solution and more ideating facilitating. And yeah, that can be tend to what we do internally, we've also had external

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facilitators come in for larger initiative. So we, I've been part of a co-design project with stakeholders all over the company where we had a third party, like a gardener come in, and help us facilitate and co-design, essentially, like our CEX program or design system. So helping us come in, because we have disparate teams for designers. Making sure that we can agree on and drive towards a singular focused vision. And that can be facilitated very differently depending on your facilitator. But there's, there's a lot of tools, like the ladder of obstruction and other things where you can get people to focus on the problem at hand more than their biases. But yeah, I don't know, I've been asked so many different ones for so many different perspectives. And I've led some many been apart, and we've had them in person, and we've had them online.

Mehnroush: How do you do co-design sessions online?

Diana: The best way we have found so far is using a software like Miro, where we can go in and Miro being the same, essentially that we can go in and collaborate together at the same time. So instead of needing to physically put stickies on a board while you're in the office, they can virtually put that sticky on, and we can talk about it and everyone feels a part of it, because they can all put their stickies on, you can bring them together. But that's been the most successful. Honestly, we tried like just a regular Zoom or WebEx and people don't talk, there's the lag, it doesn't go so well. So that's, that's the success we've seen going virtually.

Mehnroush: When you go and start the code design session before hand, you have the content or features ready?

Diana: We try to not focus on the features so much rather than the problem at hand. Then what we're trying to solve for, and in the end to come up with the features that are going to solve for that. But if we [we] don't go feature first, if that makes sense. More focus on what is the problem we are trying to solve, How like, ways that we can do that, and in the end that component as features that we can do to do it, And then we wouldn't necessarily take that way and look at the feasibility and viability of those features, [but] or desirability. But usually starting, for example, even with our care navigation, what [what] are we trying to do? At the end of the day, what are we trying to do, And what do people care about. And that's what we come up with first. And then we can use those as like a second code design session, or whichever to figure out the features that we think makes the most sense. And then we would take that away and validate them with our users before we start designing.

Mehnroush: Is there any challenges that you should expect in a co-design session?

Diana: Yes, a lot of bias. Outside of that is that the biggest challenge I found is making sure the quieter people in the room still have a voice. So some people can tend to dominate. So a lot of that from the facilitation Sessions is the with the tools that and frameworks that you choose to use that will allow those people who might not know always speak up, but might have the best ideas to really push that. The other one that I've seen quite often, at least in an older company with a lot of long tenured employees is less blue sky thinking. So more thinking about the past barriers that we've had, and not even mentioning the things that we probably should do. More or less, there's, there's that, you know, can we do in their head? So it's making sure from a facilitation perspective that you always keep checking. It doesn't matter what we did before. we just need to focus on what, what we should do. And then we will take that away and figure out how to do it. But how does it matter? It's or the why.

Mehnroush: Are there any mobile health application that you think provides good user experience?

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Diana: So one that I actually find works really well, that has been more recent is the PC Health app, where they're essentially gamifying health, which motivates people at the end of the day. It also provides, like when you go on and you [you] feel calm, when you're on there. So like, I would consider it similar to like a headspace where it's more about mindfulness of the users and getting them to do the things that they need to do. But, yeah, I think there are one of the more recent ones that's more focused on learning in terms of changing behavior, because you can't go out if you don't understand how to do it. So I do think they focus more on the educational aspect to really make that behavioral change, and focus on the problem at hand and the social determinants of health that they need to really focus on, so that we can be a more healthy and sustainable society.

Mehrnoush: What about the UI? Is it as good as UX?

Diana: Yeah, I love the UI on the PC Health app. I find that they have very inclusive imagery, for instance. So they are, they don't necessarily focus on images of people. More illustrations. So it's more abstract, so you can feel like you are a part of it, I do find the colours that they use are again, warm and welcoming. The words that they use are not negative in any capacity, and that it really does promote you to follow through with your education and remind you to do it.

Mehrnoush: Is there any way that you can improve this application?

Diana: probably for me is putting more of a sense of urgency on doing things. So I feel like it's there for me, but I get busy. So it's not necessary that I go in often, if I'm not feeling like I need to do something. So I do think it's probably that component where, you know, a lot of times you think you're healthy till you're not or other ways that they can engage people more from a day to day perspective. But other than that, I do think they do a relatively good job.

Mehrnoush: Have you ever designed an application specifically for women?

Diana: You know, we often talk about our, our main target market being women out of household. So we, that honestly is in every everything we do is thinking it tends to be that person who is on our site, and we can see that through our analytics. But we haven't necessarily delivered something focusing on it just being for women.

Mehrnoush: How do we think that designing for women is difference?

Diana: So I do think it's, it's in the content. And then probably in the imagery. So there's a lot of masculinity in the ecosystem of the world, and finding ways that you can take that out. So I've heard things like using semester is a word that sometimes can be negative for women, for instance. So I do think that is in terms of the, the images and the colours you use will be different to engage women, but also the content in a way that's taking out of it, because we do live in a very masculine world still, to be that was primarily designed and built up by men. Because people tend to design for themselves. It's very hard to move to that empathetic and compassionate view of thinking about those users and less about designing for your own [own] perspective in the moment that you're in now. So yeah, to me it's [it's it's] really focusing on words that are going to engage them, make them feel empowered. Images that are going to let them feel calm and collected and understood and isn't putting on the same pressure that tends to be in the media today, where you need to fit in this box in North America of what a woman should be. So you need to move [move] past that.

Mehrnoush: How about immigrants? Have you ever designed something specifically for immigrants?

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Diana: So I only in my [my] history designed physical prints pieces that are specifically for like new Albertans, which really was for those new immigrants. But not necessarily an app, we tend to try to be inclusive of all on the things that we're doing, because anyone can use our things. And we don't typically have products or services that are necessarily meant for immigrants only. It's just more or less, we do consider them part of our universal design process to say that someone could be here and probably respectively is that is a new immigrant and looking for health benefits. And they've never explored the health ecosystem in North America in general, let alone Alberta and Canada. And there's a lot of misconceptions between the US and us on how that that health ecosystem works, let alone the country that you probably came from. Well, I think we do always just try to consider that people [don't] might not necessarily know anything about the ecosystem, or how health how they need to navigate their health or things like how the health benefits, supplementary health benefits fit in. I find in Canada, a lot of people think you don't need them, because we do have federal [federal], provincial healthcare systems. And that they just assume that's going to, it's going to cover everything that they do need. So my long story short is, they are a piece of everything we do on just one [one] component.

Mehrnoush: What should be considered while designing for immigrants?

Diana: It's looking at it from a need's perspective. So it's more information and less insert, assuming that everyone knows how it works and taking those biases out. And again, thinking about the cross-cultural perspective of it. So when we look at it, we don't want to put, when we look at our personas, we try to, I really, really don't like when it's necessary, like put your customer hat on, it's more or less humanizing that experience. And looking at it from a way that's not going to marginalize someone by the way that we do, post something or the way that we say something. And the other part is always assuming no one knows what we're talking about. But empowering them with the way that we say that to not again, make you feel like you don't know. So we want to provide that information without making you feel like you did not know and you should know. So it's a fine balance. But at the end of the day, they're still humans, they're just coming in it from our perspective of not understanding the ecosystem, or how Canada work. And they tend to have a different native language. So always going back to, you know, a lot of people for sure, finish high school or take post-secondary in today's world. But one, that doesn't mean they want to learn how to use our site or learn health benefits. They just want you to provide them that information in a simple way that they can make that informed decision. So it's pretty much always going back to Universal Design, [making] taking biases out as much as possible, because we all know there's unconscious bias. Always making sure the content is as informational as possible without making you have to leave our site to figure it out. And then also that the way that we design the page, so are there colours that we can use that are probably negative in other cultures, and that kind of thing. Are there images that we shouldn't use because they mean something else, somewhere and trying to always validate that, again, through our own perspectives and putting it on user testing, so that we can get information that's beyond what we're assuming.

Mehrnoush: When you're doing user testing or co-design sessions do you have immigrants as part of this?

Diana: So it's, it's really interesting that you say that, because that's what we're working through right now is trying to figure out how we can include them without feeling like they're being it's more of like tokenism, or, you know, they're that always making sure we want to be diverse. So how do you be diverse without going out to your customers and saying that's why you must be part of it, and finding that balance. So sometimes they're there, sometimes they're not. And but we do really try to only accept users to our tests that are showing that diversity as much as again, assuming, especially on user testing, you don't always know who those people are based on their answers, but we can put essentially, some pre requisite questions in to try to make sure that our audiences are as diverse as possible. And then yeah, work from our customer experience perspective, we are trying to figure out how we can be inclusive in

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those panels to be anyone with a disability, or someone who is an immigrant coming into our testing as well.

Mehrnoush: Where do you go for UX design inspirations?

Diana: So for me, I probably go to the unexpected. I look all over the place for inspiration from the natural world, all the way to websites and things that have absolutely nothing to do with health. Because at the end of the day, people are not comparing health to health. They're comparing health to the things that they do in their everyday life, or they enjoy doing. So we tried to get that that perspective in to look at how we can humanize digital. So how can we still bring that human [human] factor in with engaging people, making sure we're keeping on top of emerging trends, adopting ones that makes sense for us, and then always staying true to our brand. So yeah, I do I look anywhere from, you know, interest to being out no off in a forest. And I'm like, that would be a cool shape to use, or whatever this perspective may be.

Mehrnoush: Do you have any additional comments that you feel are important to mention?

Diana: So I think for me, it would just be to brace the unexpected. You never know what's going to come in. And you never know. Just go in with no expectations of how it's gonna come out. Because once you do includes the customer and those co-design sessions, you might come out with a completely different solution than you went in with and I have seen that happen. We're like, this is the problem. That's how we solution it, gone through a few structured sessions and came out with a different, completely different problem to solve. At the end of the day. So yeah, it's to be agile, just as much as possible to go out and get as many perspectives as you can. And look at how to engage people beyond health, and bringing the health and wellness together in and what they can expect and what they can understand and what they can learn from and want to be used. So there's a lot of negativity around health. So how can you make that a positive experience? How can you make learning about this Positive but compassionate at the same time. Because at least from what you have there, there's going to be a lot of sadness in this, so embrace it. Use it and yeah, that's pretty much all I would say is I'm so excited to see if I ever do get to see what you're going to do. But I think from what, what I've learned is just that you don't know what you don't know until you all of a sudden know it and you have to adjust and be the agile, and yet the biggest part is just how you can find a truly valid user group that you can use. So you don't want to go out so and find a whole bunch of people on user testing that may have been immigrants at one point, but that was not recently. So they're probably not going to give you the same quality of information, as if you found someone who may be a recent immigrant to Canada, or wherever. So yeah, I was just, focus on finding that cocreation group, that is really a true representation of who you're going to be solving for at the end of the day. And that can be really difficult for a company or for anybody to looking and going out and user testing, because they're like, well, I tested with this person, great. You know, if they're on this site, they're probably not computer illiterate. So if we need to go out and find computer, computer, illiterate people, we need to go out and find that differently, and then different ways to test them. So they're probably not going to go on a digital platform. Or if they do, they're going to need a lot of assistance to do it. But things like user testing can allow you to do interviews, essentially, where they don't have to depend on that platform as well, where you can watch them do things. But yeah, anyways, that's just me as is really, the biggest thing that I would focus on for anybody is finding that true representation of who your customer is. And someone who can emphasize with that, so they've gone through it recently, or, you know, they're considering what it might be like. There might be fear, they might have had a friend do it, or go through it, and can really talk to that that portion of it. But for yours, too, I would probably also look at it from a healthcare providers lens. So what can they provide based on what they know? And can give it to you in an aggregate level of the things that they have questions, that they get asked that people might not realize in the moment of interviewing, that they think because again, humans are irrational. So we often do things differently than we think we do. Yeah, so often concern that but yeah, anyways, that's my [my] last speech.

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Mehrnoush: One thing is that for co-design sessions, I'm gonna do this with stakeholders, I am not allowed to have women in the, due to the limitations from ethics board. How can I solve this problem?

Diana: The tough one. So you're going to use your test with women?

Mehrnoush: Yes

Diana: Yeah, so in terms of this, then I would put them in a situation. So from a facilitation perspective, I've also I've given them essentially a situation that pulls on their emotions to get them to think about someone else. So essentially, it's like a mini case study you would use to set that stage to say, imagine you're this person. Imagine, kind of like, I'm trying to think of the mind tool, a Mind Palace. so you get them, So you use the same perspective to get them to look inward and really imagine themselves in the other person's shoes. So if you start this session with that, they're more likely going to look at it from that perspective than their own. So that would probably be what I would. What I would suggest if you can't get the actual people is to start with the visualization of getting them to be in the other person's shoes and putting them in the moment that that person would be on looking for that information.

Diana: Yeah, I would just set out the roles, responsibilities and general guidelines and outcomes of what you're looking for, and set the expectation to what we'd be doing in that session. How they can participate. How everyone's part of it. It's collaborative space. everyone's opinion is valid. No idea is a stupid idea. And no question is a stupid question. And making sure that you always said it that way, is what I would do from a content perspective. And I think I think everyone would be pretty good after that.

## 7.3 Design Material

### 7.3.1 Interview Data Analysis Summary

Topic	Description	Participate quote
Lack of physical and emotional care after a miscarriage	Women do not receive enough care after a miscarriage.	<i>It's not patient-centred or woman-centred when it comes to managing anything that's not acute. Anything that's not life-threatening. It's, I feel like patients are left in the dark to kind of struggle and manage for themselves. - Tam</i>
Lack of access to reliable information	Women do not have enough access to reliable and valid information to manage their physical and mental health after a miscarriage.	<i>a lot of times, they have a lot of really wrong information about why this happened. - Walker</i>
Cultural and language barriers	Cultural and language barriers affect immigrant women's experience of a miscarriage.	<i>Considering like different cultural practices and ways that people think about loss and like grieving and how they deal with that, I think it's important that we don't have like a, just one perspective on it.</i>
Gender	Miscarriage has not been studied and supported enough because it is a woman issue.	<i>the reason why we don't make any changes or expend any money on it, because it's a woman issue, I'm sorry. if this was a man issue, there'd be a lot of programs for it. There'd be a lot of things in place. - Tam</i>
Pregnancy after a miscarriage	Women should seek help after a miscarriage before starting a second pregnancy.	<i>pregnancy after early loss, Holy Hannah is that important because that's super highly correlated with postpartum anxiety and depression. And Peri partum anxiety and depression for sure. - Aanderson</i>

*Appx 1: Interviews with experts (obstetricians/gynecologist, psychologist, grief counselors/opportunities)*

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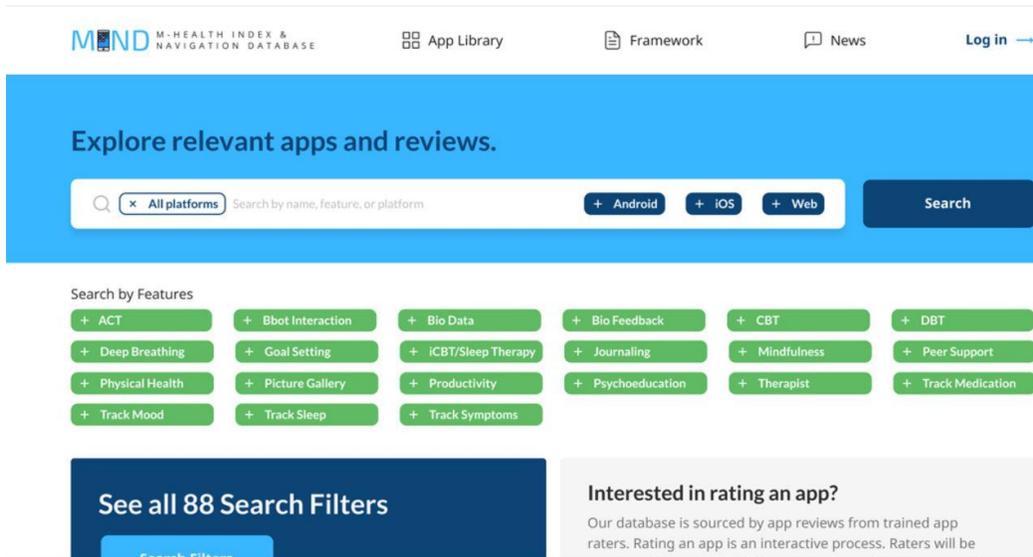
Topic	Description	Participate quote
Normalizing the experience	Normalizing the miscarriage can help women feel less guilty and alone.	<i>I would say it would be important [to] for women to understand how common miscarriages are and that miscarriages usually happen, regardless of what you have or have not done. - Bader</i>
Providing resources	Women need to be provided with resources to be able to manage their mental and physical health after a miscarriage.	<i>provide women with resources so that they can be empowered to learn about it and understand what's going on and make sure those resources are reliable, and not just anything they Google and ensure that those resources are holistic. - Tam</i>
Physical support	Providing physical support for women has the potential to help them in their recovery.	<i>it's really important to have that physical support, you know, and how to manage some of the physical changes that are going on with your body. And a lot of times that is the what people need most to begin with. - Walker</i>
Emotional support	Women need emotional support after a miscarriage to better manage their mental health.	<i>there is no right or wrong way to grieve. And don't ever let anybody tell you that you're doing it right or doing it wrong, if it feels like it's helpful for you. – Aanderson</i>
Peer support	Having a peer-to-peer network in which women can share their experience and help each other through a hard time, will help women feel less alone and scared.	<i>I just really think that women supporting women is [is] so important in cross culturally as well. And we may not know exactly what that woman needs, but we can still be empathetic. And we can listen. And we can learn. -Walker</i>  <i>sometimes it's that reality of seeing other women that are a little bit further along in their journey to know that it's not always going to be that sad. - Walker</i>

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<p>Support for partners and family members</p>	<p>Partners and family members should not be excluded from the miscarriage support.</p>	<p><i>because it's not just the woman that's going through this miscarriage, it's also her partner, possibly her extended family if she has other children, as well and what does that mean as well for them as well. -Walker</i></p>
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Appx 2: Interviews with experts (obstetricians/gynecologist, psychologist, grief counselors/ Design solutions)

7.3.2 MIND Framework



Appx 3: A Screenshot of MIND Digital Platform (<https://mindapps.org/>)

7.3.3 SES and SAQ Questionnaire (Usability Questionnaire)

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Participant name: \_\_\_\_\_ Date: / /

Age: \_\_\_\_\_

---

Overall, this task was?

	Very Difficult						Very Easy
Task 1	(1)	(2)	(3)	(4)	(5)	(6)	(7)
Task 2	(1)	(2)	(3)	(4)	(5)	(6)	(7)
Task 3	(1)	(2)	(3)	(4)	(5)	(6)	(7)
Task 4	(1)	(2)	(3)	(4)	(5)	(6)	(7)
Task 5	(1)	(2)	(3)	(4)	(5)	(6)	(7)
Task 6	(1)	(2)	(3)	(4)	(5)	(6)	(7)
Task 7	(1)	(2)	(3)	(4)	(5)	(6)	(7)

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Instructions: For each of the following statements, mark one box that best describes your reaction to the application you are using.

	Strongly Disagree					Strongly Agree
1. I think that I would like to use this smartphone application frequently.	<input type="checkbox"/>					
2. I found this smartphone application unnecessarily complex.	<input type="checkbox"/>					
3. I thought this smartphone application was easy to use.	<input type="checkbox"/>					
4. I think that I would need assistance to be able to use this smartphone application.	<input type="checkbox"/>					
5. I found the various functions in this smartphone application were well integrated.	<input type="checkbox"/>					
6. I thought there was too much inconsistency in this smartphone application.	<input type="checkbox"/>					
7. I would imagine that most people would learn to use this smartphone application very quickly.	<input type="checkbox"/>					
8. I found this smartphone application very cumbersome/awkward to use.	<input type="checkbox"/>					
9. I felt very confident using this application.	<input type="checkbox"/>					
10. I needed to learn a lot of things before I could get going with this smartphone application.	<input type="checkbox"/>					

Please provide any comments about this application.

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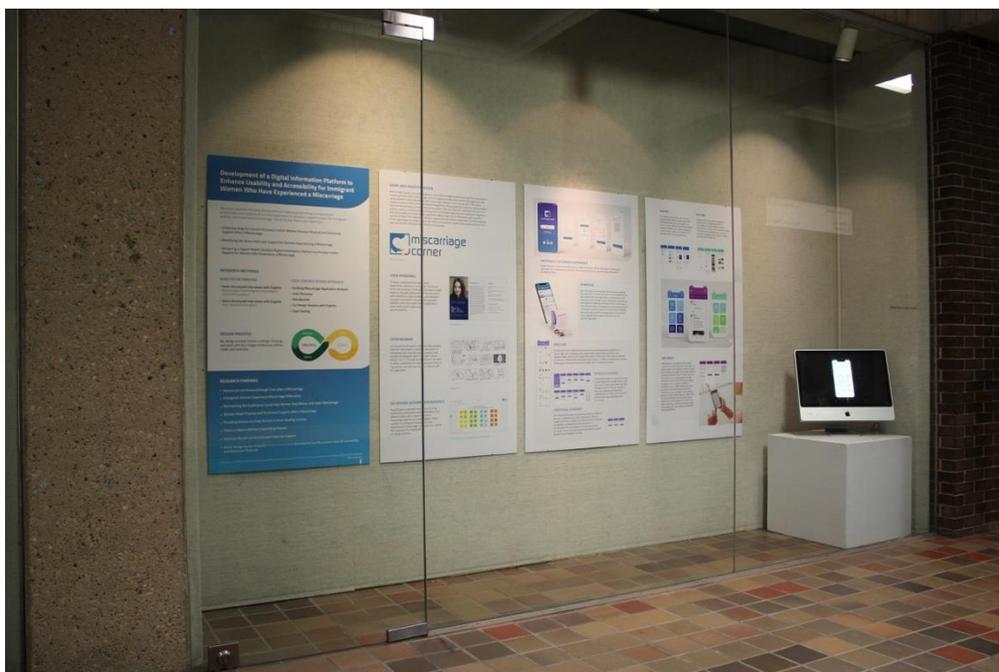
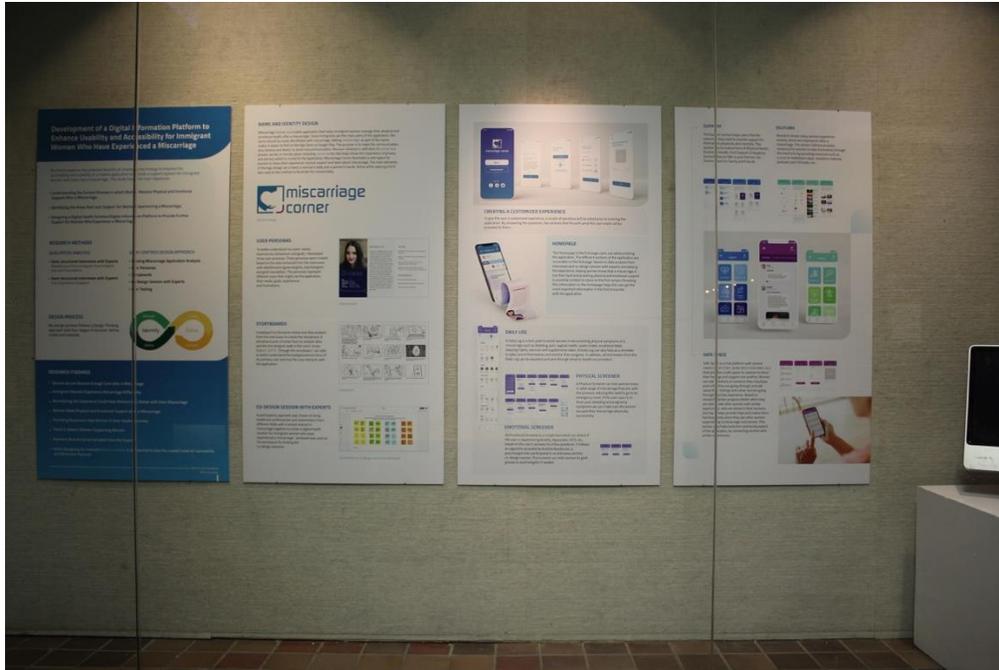
Appx 4: SEQ and SAQ Questionnaire (Usability Questionnaire)

## 7.4 Exhibition Documentation



Appx 5: Thesis Exposition: Fine Arts Building, University of Alberta

## Chapter 7: Appendices



## Development of a Digital Information Platform to Enhance Usability and Accessibility for Immigrant Women Who Have Experienced a Miscarriage

My thesis explores the potential benefits of employing technology to improve the accessibility and usability of a mobile application to provide a support system for immigrant women who have had a miscarriage. The study has three main objectives:

- Understanding the Current Process in which Women Receive Physical and Emotional Support After a Miscarriage.
- Identifying the Areas that Lack Support for Women Experiencing a Miscarriage.
- Designing a Digital Health Solution/Digital Information Platform to Provide Further Support for Women Who Experience a Miscarriage.

### RESEARCH METHODS

#### QUALITATIVE ANALYSIS

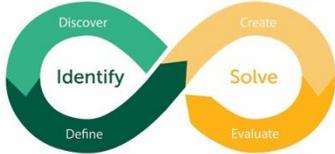
- Semi-structured Interviews with Experts  
Obstetricians/Gynecologists, Psychologists and Grief Counsellors
- Semi-structured Interviews with Experts  
User Experience Designers

#### USER-CENTRED DESIGN APPROACH

- Existing Miscarriage Application Analysis
- User Personas
- Storyboards
- Co-Design Session with Experts
- User Testing

#### DESIGN PROCESS

My design process follows a Design Thinking approach with four stages of discover, define, create and evaluate.



### RESEARCH FINDINGS

- Women do not Receive Enough Care after a Miscarriage
- Immigrant Women Experience Miscarriage Differently
- Normalizing the Experience Could Help Women Deal Better with their Miscarriage
- Women Need Physical and Emotional Support after a Miscarriage
- Providing Resources Help Women in their Healing Journey
- There is Value in Women Supporting Women
- Partners Should not be Excluded from the Support
- While Designing for mHealth (Mobile Health) it is Essential to Use the Lowest Level of Learnability and Minimum Features

Mehrnoush Zeidabadi  
MDes Student

**NAME AND IDENTITY DESIGN**

Miscarriage Corner is a mobile application that helps immigrant women manage their physical and emotional health after a miscarriage. Since immigrants are the main users of the application, the name should be easily identifiable with miscarriage. Adding **miscarriage** as part of the name makes it easier to find on the App Store or Google Play. The purpose is to make the communication very obvious and direct, to avoid miscommunication. Merriam-Webster’s definition of **corner** is a private, secret, or remote place. Including **corner** in the title helps show the importance of privacy and secrecy which is crucial for the application. Miscarriage Corner illustrates a safe space for women to share their experience, receive support and learn about miscarriage. The main elements of the logo design are a heart, a woman’s belly and a woman’s hands. Active white spacing (AWS) was used as the method to illustrate the missed baby.



Identity Design

**USER PERSONAS**

To better understand my users’ needs, experiences, behaviours and goals, I developed three user personas. Three personas were created based on the data extracted from the interviews with obstetricians/gynecologists, psychologists and grief counsellors. The personas represent different users that might use the application, their needs, goals, experiences and frustrations.

 <p><b>Diwataa</b></p> <p>Age: 27 Occupation: Student Nationality: Philippines Family: Married, no kids Education: Bachelor's Degree</p> <p>"I want this baby and I can't lose it again."</p>	<p><b>Background</b></p> <p>Diwataa is a 27-year-old woman who has gotten married 6 years ago. She moved to Canada four years ago and started working as a waitress. She always wanted to have kids, but she was not able to get pregnant. Finally, Diwataa gets pregnant and she is so happy. In the second month, she starts bleeding in the middle of the night. Her husband and Diwataa go to the emergency room, where they figure out she is having a miscarriage. After three months, Diwataa gets pregnant again. She is so afraid of losing the second pregnancy. She wants to share her feelings with her husband and her mother, but none of them is willing to talk, since they believe she should not focus on negative things while she is pregnant. She is suffering in private and tries to keep everything outside of the family.</p>	<p><b>Needs</b></p> <ul style="list-style-type: none"> <li>• Talk about her experience and share what she feels.</li> <li>• Have her feelings of concern and worry be validated.</li> <li>• Be assured about what to expect in a pregnancy after a miscarriage.</li> <li>• Know if the first miscarriage raises the chance of a miscarriage in the next pregnancy.</li> </ul>
	<p><b>Frustrations</b></p> <ul style="list-style-type: none"> <li>• Fear of losing her baby again.</li> <li>• Not being able to talk to her loved ones.</li> <li>• Feeling lonely and isolated.</li> </ul>	

User persona

**STORYBOARDS**

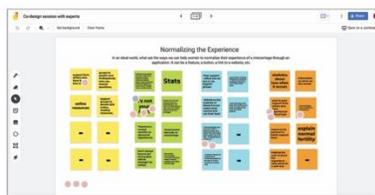
I employed my literature review and data analysis from the interviews to create the storyboard. A storyboard puts a human face on analytic data and lets the designer walk in the users’ shoes (Babich, 2017). Through the storyboard, I am able to better understand the background and story of my primary user and how the user interacts with the application.



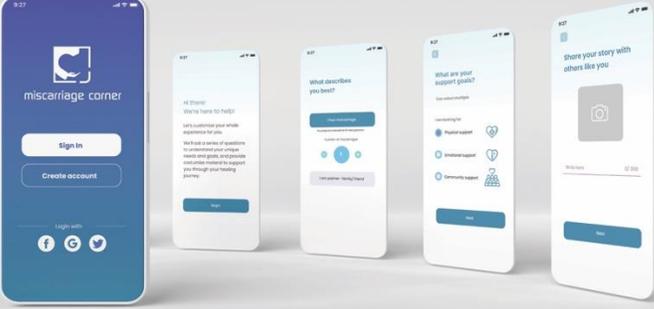
Storyboard

**CO-DESIGN SESSION WITH EXPERTS**

A participatory approach was chosen to bring healthcare professionals and stakeholders from different fields with a vested interest in miscarriage together to create a digital health solution for immigrant women who have experienced a miscarriage. Jamboard was used as the workspace for holding the co-design sessions.



Screenshot of co-design session on Jamboard



**CREATING A CUSTOMIZED EXPERIENCE**

To give the user a customized experience, a couple of questions will be asked prior to entering the application. By answering the questions, the sections that fits with what the user needs will be provided for them.



**HOMEPAGE**

The Homepage is the first page users see when entering the application. The different sections of the application are accessible on the first page. Based on data analysis from interviews and co-design session with experts normalizing the experience, helping women know that a miscarriage is not their fault and providing physical and emotional support is essential content to share on the first screen. Providing this information on the Homepage helps the user get the most important information in the first encounter with the application.



**DAILY LOG**

A Daily Log is a tool used to assist women in documenting physical symptoms of a miscarriage such as bleeding, pain, vaginal health, water intake, emotional state, sleeping habits, exercise and supplements taken. A Daily Log can also help as a reminder to take care of themselves and monitor their progress. In addition, all information from the Daily Log can be exported and sent through email to healthcare providers.



**PHYSICAL SCREENER**

A Physical Screener can help women know in what stage of miscarriage they are, with the screener reducing the need to go to an emergency room. If the user says no to fever, pain, bleeding and pregnancy symptoms we can make sure the women are past their miscarriage physically successfully.

**EMOTIONAL SCREENER**

An Emotional Screener is a simple tool which can detect if the user is experiencing anxiety, depression, OCD, etc., based on the user's answers to a few questions. It follows an algorithm provided by Kristine Aanderson, a psychologist who participated in an interview and the co-design session. The screener can refer women to grief groups or psychologists if needed.



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### Appx 7: Panel 3

#### SUPPORT

The Support section helps users find the resources they need to provide support for themselves physically and mentally. This section has six subsections of Physical Health, Emotional Health, Find Support, Emergency Contact, How to Talk to your Partner, For Partners and For Family and Friends

#### SELFCARE

Research shows many women experience anxiety, stress and depression after a miscarriage. The section Selfcare provides resources for women to help themselves through this hard time by providing resources such as access to meditation apps, relaxation material, podcasts and TED talks, etc.

#### SAFE SPACE

Safe Space is a chat platform with several rooms (YOUR STORY, BOND WITH YOUR BABY, etc.) that provides a safe space for women to share their feelings and support one another. Women can ask questions or concerns they may have, post what they are going through and talk about their feelings with other women going through a similar experience. Based on research women progress better when they are able to see other women with similar experiences, who are ahead in their recovery journey. It helps provide hope and makes them feel less lonely when they see other women experiencing a miscarriage and recover. This section also helps build the community aspect of the application, by connecting women with similar experiences.

### Appx 7: Panel 4

