EXPLORING THE EMPIRICAL AND EXPERIENTIAL LANDSCAPE OF THE PERINATAL PERIOD AFTER BREAST CANCER

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A DISSERTATION SUBMITTED TO
THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

GRADUATE PROGRAM IN PSYCHOLOGY
YORK UNIVERSITY
TORONTO, ONTARIO

August 2025

Abstract

Background: Young women with breast cancer (YWBC) cite family building as a top concern at diagnosis. While pre-treatment fertility and reproductive concerns have been well researched, little is known about the experiences of young women with a history of breast cancer (YWHBC) in the perinatal period. Additionally, YWHBC report increased distress due to the lack of information available to help navigate pregnancy and postpartum. Thus, this dissertation sought to better understand the empirical and experiential landscape of the perinatal period for YWHBC.

Methods: Study 1 entailed a scoping review of the empirical landscape regarding perinatal outcomes after breast cancer (BC). Importantly, considerations such as the impact of genetic mutations (BRCA 1 and 2), disease characteristics common for younger populations (e.g., HR+), the impact of assisted reproductive technology (ART), and breastfeeding and screening options for YWHBC were included. Study 2 consisted of a thematic analysis exploring participant perspectives regarding extant knowledge, questions, and concerns that arise for YWHBC in the perinatal period.

Results: Study 1 findings suggest that, generally, becoming pregnant after BC does not impact overall survival for YWHBC, including for women with BRCA mutations, HR+ disease, and those who use ART to become pregnant. Further, breastfeeding may be possible after BC treatment, and various screening options are possible for women who are actively breastfeeding. Study 2 revealed a number of themes related to the experiences of the perinatal period and supportive care after BC. All participants identified that increasing access to trusted, empirical information, along with tailored support resources may help to ease the psychological burden for YWHBC in the perinatal period.

Conclusions: Together, these two studies highlight the many nuanced considerations for YWHBC during the perinatal period. Study 1 helped to illuminate the empirical landscape regarding the safety of the perinatal period for YWHBC. Study 2 identified themes relating to the complex nature of having children after BC, for patients and others involved in their care, illuminating gaps in knowledge and supportive care. Ultimately, both studies will be used to inform the development of an online education tool to improve quality of care for this unique population.

Acknowledgements

First and foremost, I would like to thank my supervisor, Dr. Karen Fergus. We met in 2018 over Skype and after the first of many long and thoughtful conversations, I was so excited to join the PSO lab. It changed my life forever. Over the past 6 years, I have been continually grateful for your guidance, wealth of knowledge, and steadfast support, both personally and professionally. I am so thankful to have met and worked with you over these years.

There were many important people who consulted on this project, and dedicated their time and expertise to the development of this work. Thank you to the research team, Drs. Warner, Ladhani, and Glass for your investment in this project, as well as the folks at Rethink who supported this work. Thank you so much to Dr. Jennifer Mills and Dr. Janine Rawana for your thoughtful comments and support.

I do not think the completion of this work would have been possible without my family and friends. To Mikayla and Chelsea, your support over the course of this year kept me going. I am so proud of all of us and so happy to have had this experience together. To Sasha, thank you for answering all my phone calls and being my biggest cheerleader. To Mom and Ellen, your encouragement and steadfast support has meant the world to me over the years. Thank you for everything you do.

Finally, to all of the people who participated in this project, thank you. Your willingness to share your experiences, no matter how challenging, never ceases to amaze and inspire me. You are the reason I will keep working to improve access to care and leave the world better than I found it.

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General Introduction

Psychosocial Distress in Young Women with Breast Cancer

Breast cancer (BC) is the most frequently diagnosed cancer for women of childbearing age (45 years and younger) (Nolan et al., 2022) and remains the leading cause of death for women from the ages of 30-49 (Seely et al., 2024). Incidence rates have risen significantly in the past several decades for women in their 20s, (56.4% since 2001), 30s (12.5% since 1984), and 40s (9.1% since 1984) (Seely et al., 2024). Importantly, young women with breast cancer (YWBC) are also more likely to be diagnosed with advanced, rather than early-stage disease (Muzzati et al., 2020).

YWBCs are considered a unique group for two important reasons. First, they carry a heavier biological burden of disease. For example, this population is more likely to be diagnosed with more serious biological features such as larger tumour size, advanced tumour stage, overrepresentation of the human epidermal growth factor receptor 2 (ERBB2), hormone receptor status (e.g., estrogen and progesterone receptor), and genetic mutations (e.g., BRCA 1 and BRCA 2) - each of which contribute to an overall poorer prognosis (Xu et al., 2024). This presentation may, in part, be due to the fact that BC screening recommendations exclude women under 40 years old from regular screenings (Qin et al., 2018).

Second, young women diagnosed with BC generally experience an increased *psychological* burden after BC diagnosis and remain the most vulnerable to psychosocial distress into the survivorship period compared to other cohorts (Ahmed et al., 2015; Muzzati et al., 2020). Developmental theories may help to explain the increased distress for this population. For example, Erikson (1950) identified *intimacy* (ages 18-30) and *generativity* (ages 30-60) as two important developmental stages. *Intimacy* marks the period wherein emerging adults develop intimate relationships with others, while adults 'make their mark' during the *generativity* stage by caring for others (e.g., children). While these age ranges were more narrowly defined by Erikson, scholars have more recently suggested that such developmental milestones are more fluid, based on life experiences. Thus, the stages of intimacy and generativity may feel disrupted for YWBC at any point in their cancer trajectory and, according to Erikson (1950) lead to feelings of isolation and stagnation. Neugarten's work (1976) nicely frames Erikson's stages of intimacy and generativity, introducing the theory that disruption to the pursuit of milestones such as education, career development, and family planning, are particularly distressing. For YWBC, they are necessarily forced to pause these pursuits, instead having to focus on cancer treatment and health. More recent studies with YWBCs highlight the distress that disruption in expected stages can have, which impact their daily functioning and quality of life. For example, one study found that, compared with population norms, social and role functioning was impeded for young women with a history of cancer (Fernández de Larrea-Baz et al., 2020). Additionally, YWBC cite distress related to disruptions in education and career advancement, as well as challenges with family planning and fertility (Ahmad et al., 2015). Studies have also found that YWBC experience a profound sense of isolation both within their own peer groups as well as the broader BC community, which highly correlates with increased levels of depression and anxiety (Ahmed et al., 2015; Liu et al., 2021).

More broadly, a history of BC can lead to increased depression, anxiety, and body image concerns (Niedzwiedz et al., 2019; Goerling et al., 2020), as well as hyperattention to pain and changes in the body (Stanton et al., 2015). Fear of cancer recurrence (FCR) is another significant source of distress that this population must manage after diagnosis (Sun et al., 2019) and is consistently shown to be more prevalent in younger women compared to their older counterparts (Geue et al., 2017; Bergerot et al., 2018). One recent study found that a third of YWBC showed moderate to high levels of FCR that persisted over 5 years after diagnosis (Schapira et al., 2022).

Despite the increase in diagnosis, medical advancements in local and systemic treatment, in combination with screening and BC detection, have significantly improved both survival and recurrence rates for YWBC (Nolan et al., 2022). Mortality due to BC has shown a steady decline over the past three decades (Seely et al., 2024) but these advancements have led to increasing numbers of YWBC who are left to navigate survivorship, including completing their family planning goals.

Family Planning

A top cited concern for YWBC is the possibility of reproduction after treatment (Waimey et al., 2015; Hu et al., 2024). In fact, a recent meta-analysis analyzing concerns for YWBC around the world noted that 53% of YWBC voice fertility concerns throughout the cancer trajectory (Chen et al., 2023)[1]. Perhaps appropriately then, the majority of research on YWBC has focused on issues around infertility and fertility preservation. The attention on fertility as a survivorship issue for YWBCs has been integral in better understanding the impact of primary treatment on reproductive function, as well as young women's fertility goals after treatment (see Waimey et al., 2015). For example, chemotherapy is a standard treatment for BC but has associated gonadotoxic effects such that the treatment may permanently impair fertility, causing premature ovarian failure or triggering menopause (Waimey et al., 2015). Medical advancements and standards of care now include options for fertility preservation including oocyte and egg

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[1] Those who did not cite fertility as a top concern were partnered and/or already had one or more children at the time of diagnosis (Chen et al., 2023). Additionally, higher levels of education were correlated with increased fertility concerns; likely related to the fact that their informational needs were not satisfied (Chen et al., 2023).

freezing (through both government funded programs and charitable initiatives), as well as ovarian suppression drugs taken in conjunction with chemotherapy to preserve ovarian function once the body has recovered (Moffat & Güth, 2014; Hong et al., 2023). Such research has also led to the development of educational and knowledge translation tools that can help aid YWBC in making pre-treatment fertility decisions (e.g., The Oncofertility Consortium).

While, significant progress has been made in the area of fertility research and support, there is now a widening gap in knowledge and care between pre-treatment fertility preservation, and the process and experience of conception and the perinatal period (conception to 5 years postpartum) for this population. Therefore, the focus of this dissertation is on the post-treatment experience of, and concerns regarding, the perinatal period after primary BC treatment.[2]

Reproductive Concerns and Considerations After Primary BC Treatment

Global trends show that women are delaying pregnancy to later in life due to factors such as completing education, participating in the work force, psychological un-readiness, and health issues (Safdari-Dehcheshmeh et al., 2023). In fact, the global maternal age has risen by 5 years and fertility rates in women over 35 years old have increased approximately 10% since 1990 (Iqbal et al., 2017). Therefore, it is likely that some YWBC will receive a diagnosis of cancer before they have completed their childbearing goals and may be taking medications (e.g., Tamoxifen) that further extend the age of childbearing after primary BC treatment (i.e., at least 2 years after beginning endocrine therapy) (Patridge et al., 2023).

While the global trend of voluntary delayed pregnancy increases educational and financial opportunity for women, it also may work against YWBC given that many of this cohort will not have begun pursuing or completed their family building goals at the time of diagnosis.

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[2] Please see the Ch. 2 for a brief elaboration of fertility related concerns in this population.

Young women with a history of breast cancer (YWHBC) who pursue family building goals may experience unique challenges that have not be adequately addressed. For example, women must weigh choices such as interrupting hormone therapy to become pregnant (Patridge et al., 2023), genetic considerations for BRCA carriers (Lambertini et al., 2020) and navigating breastfeeding after primary BC treatment (Azulay-Chertok et al., 2020). In fact, some studies show that some YWHBC may act counter to medical advice in order to carry out their perinatal goals (e.g., breastfeeding beyond recommended timelines, not completing course of endocrine treatment) (Patridge et al., 2023). Some studies even show that YWHBC may choose to forgo treatment altogether (e.g., endocrine treatment) in favour of prioritizing their family planning goals (Partridge et al., 2023; Lewinsohn, 2024).

While there is no evidence that pregnancy (Buonomo et al., 2020) or breastfeeding (Azulay et al., 2020) increase the risk of cancer recurrence, YWHBC may still experience heightened psychological distress in relation to these factors both when considering becoming pregnant, and during pregnancy (Hu et al., 2024). Studies show increased fear and anxiety around cancer-related concerns such as passing down cancer genes, fetal abnormalities due to treatment, and finding or noticing changes in lactating breasts (Azulay et al., 2020; Di Mattei et al., 2023). Distress such as anxiety, anger, and fatigue may also increase during this time (Faccio et al., 2020; Schwab et al., 2021). Such distress is reported to be present at various stages across the reproductive trajectory after BC including when women engage in family planning (Arumand et al., 2018), during pregnancy (Azulay et al., 2020), and into motherhood (Ares et al., 2014).

Again, despite the incidence of increased distress, it is now ever more possible for young women with a history of breast cancer (YWHBC) to become pregnant. New data have suggested that women who are able to conceive after BC treatment are shown to have a similar or increased timescale from time of diagnosis to matched controls (both naturally and using assisted reproductive technologies), showing no evidence that YWHBC have a shorter time with which to conceive (Anderson et al., 2022). Further, prevalence rates of pregnancy show a significant increase in the number of YWHBC who are able to conceive after treatment. While these numbers remain low compared to the general population (between 4-8.6% of BC patients will achieve live birth after diagnosis which is approximately 40-60% less than the general population) (Bae et al., 2022, Lambertini et al., 2021), a recent study cited two-thirds of BC patients diagnosed with early stage disease achieved live birth after primary treatment (Sorouri, 2024).

Imperative for Resource Development

Given the heightened disease burden and increased vulnerability to distress during pregnancy, there is a clear need to better understand both the experience of and supportive care needs for YWHBC who enter into the perinatal period. While physical and psychological health are key areas of concern, another important consideration for this population is their access to resources. One review study found that health system information and psychological resources represented the greatest area of need for YWBC when navigating the survivorship period (Fiszer et al., 2014). Similarly, our previous research found that women in the perinatal period with a history of cancer cited lack of resources regarding pregnancy and postpartum as a major source of distress post-treatment (Vanstone et al., 2021). Another study found that lack of access to empirically supported medical information regarding breastfeeding (or no information) exacerbated worries for YWHBC and that they experienced various post-BC feeding challenges (Azulay-Chertok et al. 2020).

Evidence shows that, in general, YWHBC have very few support resources as age-related care still focuses mostly on fertility preservation and treatment (Partridge et al., 2015). One of the major problems for this niche population is that there is a dearth of high quality, empirically supported information to guide navigation through the perinatal period. A recent meta-analysis of pregnancy after BC highlighted that most study results are based on retrospective, observational data making it difficult to provide specific and tailored counseling to this population (Lambertini et al., 2021).

Thankfully, increased attention to reproductive concerns in survivorship is becoming more commonly addressed in pre-treatment appointments for YWBC, leading to more access to resources as women begin their cancer journeys. For example, the PYNK program in Toronto, Canada is focused on addressing unique needs for YWBC including identifying reproductive concerns pre-treatment, with the goal of empowering the population to make agentic treatment decisions with regards to their reproductive wishes *after* BC treatment (Vuong & Warner, 2024). Such hospital and community programs are becoming more common for this population (Yufe et al., 2025). However, women still cite lack of access to trusted resources specifically those addressing *perinatal* concerns (Hu et al., 2024). While international guidelines recognize the need for tailored support during the prenatal period for YWHBC - stating that care providers should refer to ‘psychosocial support’ where needed - they fail to provide specific resources (Cardoso et al., 2023). Without adequate support, resources, and knowledge, patients may experience increased overwhelm and worry about how to navigate the perinatal period.

Implementation Science and the Current Study

Implementation science is an important link bridging research and knowledge with resource use. While many effective interventions may enhance quality of life for YWHBC, they are of no benefit if they cannot be delivered to those in need. Health research has evolved and shifted to focus on implementation strategies that have positive implications for improving public health, specifically in the wake of increasingly dynamic and resource-constrained conditions (e.g., lack of hospital funding) (Implementation Science at a Glance, National Cancer Institute, 19-CA-8055, 2024). Implementation science helps to determine the most effective resource development in various health arenas in order to increase access and fidelity to resources and interventions. The National Cancer Institute (2024) highlights the need to engage various stakeholder groups in resource development to improve successful implementation of said resources (e.g., interactive assistance, supporting practitioners, training and educating stakeholders). Ideally, diverse stakeholder engagement results in development of tools that can be flexibly adapted for the population in question, in this case YWHBC who are navigating reproductive concerns.

This dissertation presents two studies which broadly address concerns and needs for primary stakeholders during the perinatal period after BC, including YWHBC, healthcare providers, and community partners. Study 1 is a scoping review of the landscape of current evidence broadly relating to perinatal outcomes for YWHBC. While there are meta-analyses and systematic reviews showing the general safety of pregnancy after BC treatment (Lambertini et al., 2021; Arecco et al., 2023), little synthesization of knowledge exists regarding considerations such as safety of pregnancy for specific types of BC disease (e.g., ER+, BRCA carriers), timing of pregnancy and subsequent maternal and neonatal outcomes, and breastfeeding and screening considerations. Therefore, our analysis sought to highlight all available evidence to fill such gaps in research representation in English speaking regions.

Study 2 consists of a qualitative, reflexive thematic analysis aimed to better understand current knowledge, questions, and concerns for primary stakeholders (YWHBCs, providers, community partners) in relation to the perinatal period after BC. In particular, we were interested in the following domains: 1) common questions and concerns that patients have about pregnancy and birth outcomes after initial BC treatment and how BC uniquely impacts the perinatal period; 2) extant knowledge of healthcare providers (OB/GYNs, fertility specialists, oncologists, family doctors, nurses) regarding the safety of reproduction after initial BC treatment; 3) community based supportive programs that address reproductive issues; and 4) information that would be helpful to know prior to, and throughout, the perinatal period to alleviate uncertainty and associated distress.

In combination, these two studies are aimed toward the goal of establishing an implementation resource: an online educational tool specifically addressing stakeholders' reproductive concerns for YWHBC. The tool will ultimately be designed to increase knowledge translation, improve patient health literacy and empowerment, and bolster the continuity of care for this population.

Chapter 2 - An Exploration of the Perinatal Period for Young Women with a History of Breast Cancer: A Scoping Review of the Empirical Landscape

Introduction

Young women with breast cancer (YWBC) are described as the "minority group with the majority need" (Ahmad et al., 2015). This description speaks to the psychosocial challenges that YWBCs face after primary treatment that are unique to their age group. For example, YWBC may struggle with body image, relationship distress, and fear of cancer recurrence as they navigate the post-treatment period (Ahmad et al., 2015) and show increased levels of anxiety and depression as compared to their older-aged counterparts (Niedzwiedz et al., 2019, Crist & Grunfeld, 2013).

Another unique consideration for young women with a history of breast cancer (YWHBC), defined throughout this paper as women under the age of 45 years who have completed primary BC treatment, is the initiation or continuation of family building, expressed as a top concern for this population (Goncalves et al., 2017). In fact, research suggests that some patients may prioritize fertility and pregnancy over recommended treatments (e.g., chemotherapy, hormone therapy) (Hong et al., 2023). Doing so is not unwarranted given the potentially detrimental effects of treatment on reproductive ability (Hartnett et al., 2018). For example, chemotherapy and radiation may damage healthy, immature egg cells and disrupt female hormone production (Roberts et al., 2015). Additionally, hormonal therapies to improve rates of survivorship for women with estrogen receptor positive (ER+) disease disrupt embryo or fetal development and are contraindicated during pregnancy (Shandley et al., 2017).

Perhaps because BC treatment can be so detrimental to fertility, the wish to pursue family building goals may become even more pronounced after primary BC treatment (Waimy et al., 2015). Particularly for individuals who cite the ability to pursue pregnancy as a pre-treatment concern, disruption in fertility may negatively impact YWHBCs psychological wellbeing after treatment. For example, one study showed that women who experience disruption in their reproductive ability after cancer treatment have increased symptoms of depression (Di Mattei et al., 2023). The psychological distress regarding fertility and pregnancy for this population highlights the importance of addressing such concerns.

Thankfully, more attention has been paid in recent years to supporting YWHBC (i.e., support in the survivorship period) and international guidelines now call for multidisciplinary support to address age-appropriate care (Cardoso et al., 2024). One major area of development has been in fertility. Although more recent studies continue to cite fertility as a major concern for YWBC (e.g., Hong et al., 2023, Goncalves et al., 2017), fertility preservation (FP) is becoming a standard of care for this population (Yang et al., 2023). Fertility preservation techniques for people who were identified female at birth may include pre-diagnosis mature oocyte/embryo cryopreservation, ovarian tissue cryopreservation, ovarian suppression with Gonadotropin-Releasing Hormone (GnRH) agonists, and in vitro oocyte maturation (Yang et al., 2023). For example, GnRH agonists may be offered to patients prior to treatment to suppress GnRH, a natural hormone involved in supporting reproductive functioning. GnRH agonists and antagonists help to shut down and protect the reproductive system in hopes of preserving fertility (Yang et al., 2023). Post-treatment cryopreservation may also be an option depending on the treatment (Yang et al., 2023).

In addition to medical options, tools to aid in FP decision-making have become widely available for patients (see https://fertilityaid.rethinkbreastcancer.com/ for an example of a FP information decision aid). Educational tools offer patients access to relevant information about their care through interactive, online formats, which provide up-to-date and readily accessible information and support (Clifford et al., 2017). Access to such tools assists in collaborative decision-making between patients and their healthcare providers. Further, they are linked to improved mental health (Andrykowski et al., 2008) and significantly increased knowledge and trust in healthcare providers (Rising et al., 2018). These dedicated tools are intended to help YWBC plan for their future beyond acute BC treatment to improve quality of life into survivorship (Qin et al., 2023).

Pre-treatment fertility preservation is an important step in the cancer journey for YWBC for two reasons. First, it may reduce post-treatment distress. Studies show that a lack of fertility options can lead to decision regret and feelings of loss post-treatment (Canzona et al., 2021). While such decisions may feel difficult to make in the pre-treatment phase, given patients' primary focus on survival, YWBC still express the need for information and resources regarding fertility (Wang et al., 2020). Second, FP treatments have practical implications for post-treatment family building. For example, one recent study showed that fertility preservation before BC treatment increases the chances of YWHBC becoming pregnant (Marklund et al., 2021), making access to FP imperative for women who wish to pursue pregnancy post-treatment. Further action has been taken to help support this population by supplementing costs of FP for YWBC. In 2022, the Government of Canada introduced a tax credit to help subsidize fertility costs related to medical procedures (including cancer treatment). Fertility coverage is now available through public health in six provinces, with others offering alternative fertility resources (Government of Canada, 2024). However, while fertility preservation has been a priority for government and medical institutions, there remains a gap in care for YWHBC who achieve pregnancy.

Pregnancy Considerations after Primary BC Treatment

There is ample research addressing BC diagnosis *during* pregnancy (see Shao et al., 2020), yet pregnancy *after* BC has been a generally neglected area of research in oncology. While the numbers of pregnancies carried to term remain low (e.g., between 3-8% of YWHBC), those who can do so are left with questions and concerns regarding the perinatal period (from conception to 5 years postpartum) that may not have been adequately addressed (Bae et al., 2022). Recent research has shifted to begin focusing on the survivorship period for YWHBC, including considerations for pregnancy. One major finding is that pregnancy after BC treatment is safe (Gerstl et al., 2018). Such research has been used to develop international guidelines that help to inform healthcare providers to counsel their patients who wish to pursue pregnancy. For example, guidelines do suggest delaying pregnancy by at least 2 years after completing primary treatment due to the likelihood of recurrence within that time period (Cardoso et al., 2024). However, widely available information regarding the perinatal period after BC provides only general guidelines to a population whose individual presentation (e.g., cancer type) may have different implications during pregnancy (see below). Previous studies have shown that a main source of distress for YWHBC in the perinatal period is the lack of information available to them (Vanstone et al., 2021), cited as the second most common concern after psychological needs (Khajoei et al., 2023). Although the ability to engage in family building is considered an important factor in improved quality of life for many survivors, the lack of tailored information to guide women through the perinatal period may lead to increased anxiety and fear of recurrence (Wang et al., 2020). This distress implies that general information, while helpful, is not sufficient to address YWHBCs' needs given the various considerations this population must contemplate.

Of particular concern for YWHBC in the perinatal period may be individual disease characteristics that lack sufficient attention in the research. For example, women diagnosed before the age of 45 years are more likely to have an inherited BRCA 1 or 2 mutation. Notably, 69% of BRCA 1 mutations lead to hormone receptor-negative disease, also referred to as ‘triple negative’ BC which is notoriously more aggressive and difficult to treat and has higher rates of metastasis and recurrence (Chen et al., 2018). Carriers of the BRCA 2 mutation are more likely to have hormone receptor-positive breast cancer (HR+). While easier to treat, women diagnosed with estrogen/progesterone receptor positive disease may be counselled to undergo 5-10 years of endocrine treatment, which is contraindicated with pregnancy (Partridge et al., 2023). The imposed delay in family building may mean that women who comply with treatment recommendations may wait up to 10 years after primary treatment before having the chance to attempt conception. More recently, research has been focused on whether interrupting hormone therapy for the pursuit of pregnancy is safe (Partridge et al., 2023).

Individual disease characteristics such as BRCA mutations imply the need for tailored information for YWHBC who pursue pregnancy. For example, YWHBC cite concerns about passing down inherited BRCA genes and the impact this may have on the developing fetus (Vanstone et al., 2021). BRCA carriers also show increased fear of recurrence (Michel et al., 2024), which may be more pronounced in the perinatal period (Tran et al., 2021). Women with HR+ disease may worry about the impact of increased hormones during pregnancy on recurrence. Worry may be especially pronounced for YWHBC relying on artificial reproductive technologies (ART) (e.g., IVF) to become pregnant, as such treatments necessarily increase hormone production (Lambertini et al., 2017).

Postpartum Considerations after Primary BC Treatment

Beyond pregnancy, concerns arise regarding the feasibility of breastfeeding. Surgery remains the primary form of treatment for BC diagnoses and includes a variety of options, depending on the size and location of the tumour. For example, breast-conserving surgeries, referred to as lumpectomies, refer to removal of the cancerous tumour and some surrounding breast tissue, which preserves the majority of the breast (Czajka & Pfeifer, 2025). Some women may also have the option to undergo oncoplastic surgery, which combines tumour removal with breast reshaping. This option is done to improve the look and shape of the breast post-treatment. The post-operative appearance of the breast is directly related to how much tissue is removed (American Cancer Society, 2021). The options available for partial removal of the breast and breast tissue make it possible for women to breastfeed from the unaffected breast and may be possible from the affected breast (Johnson & Mitchell, 2019). In addition, some women will require a mastectomy (removal of the entire breast), or double mastectomy (removal of both breasts) (Czajka & Pfeifer, 2025). A double mastectomy may be required if cancer is present in both breasts, but it is also common for women diagnosed with the BRCA gene who may wish to have preventative surgery given their higher risk of recurrence (American Cancer Society, 2021).

While surgery is generally the first-line treatment for YWBC, many require a sequence of other treatments (e.g., chemotherapy, radiation) depending on the size, location, and grade of tumour, and whether it has spread to the lymph nodes - to prevent recurrence (American Cancer Society, 2021). Radiation and chemotherapy do not necessarily prevent breastfeeding, but women may be left with questions about the safety of breast milk for their child (Johnson and Mitchell, 2020). Given the range of treatment options for YWBC, and the possibility of lactating from a treated breast during pregnancy, YWHBC often have questions regarding how to monitor changes in the breast in the postpartum period, specifically if they produce colostrum (the first form of breastmilk). Finally, YWHBC may also have questions regarding the safety of routine screening during breastfeeding, or, for women who are unable to breastfeed due to a double mastectomy, questions regarding the safety and sufficiency of using formula in place of breast milk. (Johnson & Mitchell, 2019, Johnson et al., 2018).

It is clear from the literature that there are many unanswered questions for YWHBC who become pregnant. However, it is not just patients who are lacking necessary information during the perinatal period. This void of information is also reflected in healthcare settings. Studies show that, while knowledge is improving (see Kelvin et al., 2016), physicians directly involved in BC care continue to hold misconceptions concerning pregnancy and birth outcomes after primary BC treatment (Lambertini et al., 2019), and oncofertility in general (Warner et al., 2016). Unfortunately, such misconceptions may preclude primary care providers from adequately counseling their patients, which in turn increases patients' psychological distress (Lambertini et al., 2019). Therefore, both patients and providers would benefit from targeted informational tools similar to those available for fertility preservation to help ease psychosocial distress as YWHBC enter into the perinatal period.

Current Study

YWHBC continue to cite increased distress in response to limited information regarding the perinatal period (Vanstone et al., 2021) and report a lack of support and resources regarding pregnancy and breastfeeding specific to their individual concerns (e.g., age, disease type, treatment history) (Azulay et al., 2020). Similarly, healthcare providers may not have up-to-date evidence regarding the perinatal period after primary BC treatment. Thus, the aim of Study 1 was to conduct a scoping review with the goal of identifying and amalgamating empirical data regarding the perinatal period for YWHBC. Specifically, we were interested in synthesizing new and emerging research findings (e.g., impact of HR+ disease on pregnancy outcomes) pertaining to more granular outcomes that have not yet been widely explored or discussed (see Table 1 for a breakdown of such topics). Conducting a scoping review allowed us to cast a wide net to explore emerging research in the field, and to represent a heterogenous area of research rather than focusing on a narrow topic as per a systematic review. Ultimately, the aim of this review was to summarize current evidence to help patients and providers better understand treatment decisions prior to and throughout the perinatal period. The results of the scoping review will serve as the empirical foundation of our online education tool, promoting communication between patients and providers to better serve and empower YWHBC.

Research Questions

In particular, we were interested in under-researched questions and concerns that arise for YWHBC. Our research questions were developed in collaboration with the research team consisting of specialized care physicians working directly with YWHBC (e.g., oncologist, fertility specialist, OB/GYN). In addition, RV spoke directly with one YWHBC (a former patient of one of our research team members) regarding her experience of the perinatal period after breast cancer treatment. She described general questions or concerns that arose during the perinatal period that were important to know or that she wished would have been addressed. These areas of concern or interest influenced the selection of search terms. Directed by preliminary literature searches, as well as professional and patient expertise and input, our research questions were as follows:

1. How do individual disease characteristics (e.g., BRCA mutations, HR+ disease) impact pregnancy outcomes?

2. How do individual disease characteristics (as above) influence recurrence rates?
3. What impact does BC treatment have on breastfeeding and breast screening for YWHBC?

Methods

The aim of this study were to explore the landscape of empirical literature regarding issues that pertain to the perinatal period for women who become pregnant after primary BC treatment. Our assumption was that there would be well-established outcomes and guidelines related to general concerns (e.g., safety of pregnancy after BC) but that papers addressing more nuanced outcomes, such as the impact of BRCA mutations on pregnancy outcomes, would be limited. The goal was to amalgamate empirical research that reported on these more specific considerations. The study was reviewed and approved by both the Sunnybrook Research Ethics Board (5142) and the York University research ethics board.

After consulting with a librarian at York University, consensus was reached on conducting a scoping review of the literature. Given the breadth of available studies on this topic, the interest in outcomes beyond the safety of pregnancy (e.g., time to pregnancy, disease status, breastfeeding), and the exploratory nature of the study, a scoping review was selected as the method of choice in order to better understand and map less commonly discussed and understood concerns on the topic of “kids after breast cancer.” A scoping review is an intrinsically exploratory process that is intended to better understand certain concepts and gaps in research through thematic amalgamation of data (Colquhoun et al. 2014). Generally, scoping reviews are chosen for a field of interest that is broadly defined and may act as a precursor to systematic reviews when there is newly emerging evidence on a particular topic that has not been studied sufficiently to warrant a systematic review (Munn et al., 2018). Doing so allows for a broad review of the literature that is less clinically driven and does not necessarily include an evaluation of study quality (Arksey & O’Malley, 2005). Scoping reviews can be particularly important for synthesizing broad areas of healthcare research and are often relied upon to develop evidence-based clinical care guidelines (Munn et al., 2018). The process of defining our scoping review involved selecting a range of research studies with predefined criteria and a search strategy based on our research questions (above). The intended result encompasses a synthesis of current knowledge in the area of interest: in this case, perinatal considerations for YWHBC. Given that our aim was to identify perinatal outcomes that have not been extensively explored (e.g., based on various disease characteristics, treatments, and timepoints in the perinatal period), a scoping approach allowed for heterogenous data synthesis, as well as necessary modification of search terms throughout the search process if deemed necessary (Peters et al., 2021). Ultimately, the current study did not modify the original search terms.

The development of the current search strategy was guided by the PRISMA-ScR guidelines (Tricco et al., 2018) in collaboration with a York University Faculty of Health librarian in the spring of 2022. The scoping review framework includes five distinct steps as defined by Arksey & O’Malley (2005) – 1) identifying the research question(s), 2) identifying relevant studies, 3) selecting relevant studies, 4) charting data, collating, and summarizing, and 5) reporting results (Arksey & O’Malley, 2005). We began by defining our research questions, which helped to guide the eligibility criteria (listed below). Eligibility criteria were broad to capture all relevant studies in the area of interest.

Our assumption was that the search would produce limited data, thus our initial searches remained as broad as possible in order to ‘catch’ studies that included any information regarding outcomes related to the perinatal period after primary BC treatment, such as the rates of recurrence for different disease types (e.g., ER+), birth outcomes for both mother and child, and breastfeeding challenges. Additionally, we included case studies and grey literature (e.g., published dissertations, conference abstracts) to ensure that we were capturing emerging research not yet published in peer reviewed journals. RV and the librarian began by conducting several broad searches to gauge the quantity of studies produced and narrowed our search strategy thereafter. For example, we began by searching “breast cancer history” AND “pregnancy” AND “postpartum” in Medline. Doing so allowed us to determine the appropriate search terms (MeSH terms) to refine our final search strategy listed below. RV, with the help of three research assistants trained on our search strategy, completed searches in our predetermined databases: 1) PubMed, 2) Medline, 3) Scopus, and 4) PsycINFO. Articles were selected at this stage based on title review. The final search terms for each database included the following: “breast cancer treatment history” OR “chemotherapy” OR “radiation” OR “surgery” OR “hormone treatment” AND “pregnan*” OR “postpartum” OR “perinatal” AND “birth outcome*” OR “cesarian section” OR “complicat*” OR “still birth” OR “live birth” OR “vaginal birth” OR “miscarriage” OR “abortion” OR “spontaneous abortion” OR “breastfeed*” OR “screening”. The following filters were applied: “English language”, “January 1, 1965-Present day”. We included a large date range in order to capture articles (e.g., case studies) that may have been otherwise missed. The final database searches included in the study occurred from August-September 2023. Additionally, RV searched well-established websites (e.g., Canadian Cancer Society, Dana-Farber Institute) for additional grey literature (e.g., references to unpublished studies), which are often referenced in short articles before journal publication.

Inclusion and Exclusion Criteria

The following inclusion criteria were determined for the database searches: 1) the study included women aged 45 years or younger with a history of breast cancer who are in the perinatal period (defined as beginning from conception up to 5 years postpartum), 2) the study only included women who received and had completed primary breast cancer treatment, 3) the study also included women who are/were receiving hormone therapy after primary breast cancer treatment, though receiving hormone therapy was not necessary to meet inclusion criteria 4) the study could be of any type (e.g., longitudinal, retrospective, qualitative, case study) and measured outcomes related to the perinatal period after primary breast cancer treatment, and 5) English language publications. Outcomes of interest included: medical guidelines regarding the perinatal period after primary BC treatment, rates of recurrence for different disease characteristics, pregnancy/birth outcomes after primary BC treatment (e.g., miscarriage, still birth, live birth), and breastfeeding outcomes. The exclusion criteria included: 1) studies that included women above the age of 45 years, 2) studies that included patients for whom breast cancer was diagnosed *during* pregnancy, 3) studies with women who used fertility preservation options prior to primary BC treatment (e.g., oocyte preservation, GnRH), 4) studies that included women currently in primary treatment, 5) studies that included women with metastatic disease, and 6) non-English language publications. Studies that included women with metastatic disease were excluded for two reasons. First, metastatic disease may introduce treatment variables that differ between women with metastatic disease versus women who have completed primary treatment (e.g., ongoing drugs for metastatic disease management such as hormonal therapies with or without the option or oncologist support to cease treatment to become pregnant). Second, metastatic disease may have unknown physiological consequences that impact pregnancy and pregnancy outcomes and which differ for women engaging in ongoing treatment versus those who have completed treatment. Qualitative studies were included to glean understanding of the types of issues and questions that come up for patients, though none were included in the final analysis.

Selection Process

After the initial selection process, RV, together with one of the research assistants, determined article eligibility in two stages. The first stage included abstract review using the eligibility criteria. At this stage, reviewers began using Covidence as recommended by the York University librarian. Covidence is a screening and data extraction tool used to conduct both systematic and scoping reviews. The tool was used by both reviewers separately, flagging articles that required conflict resolution and/or further discussion. After the first stage of screening, the reviewers met to discuss any conflicts identified in the initial stage of the process. Conflicts were ultimately resolved and the reviewers moved on to stage two. This stage included full text review for those studies that met criteria in stage one. During stage two, each article was screened for outcomes pertaining to the perinatal period after primary breast cancer (BC) treatment. The reviewers again met several times throughout the process to discuss conflicts. During one meeting, both agreed that meta-analyses and systematic reviews be excluded from the article selection given they already filled a gap in the literature that could be used to inform the ultimate education tool (e.g., general neonatal outcomes, general outcomes from assisted reproductive technology after primary BC treatment). While this type of data are ultimately important to report, our focus was on finding and amalgamating understudied/underreported outcomes for YWHBC. However, several review papers were included if they added to our understanding of the perinatal period after BC. Once the reviewers had reviewed 10 articles each, the team met to determine any additional exclusion criteria. These criteria included: 1) meta-analyses and systematic reviews, 2) studies that summarized published meta-analyses or systematic reviews, and 3) articles that reported outcomes on mixed-disease sites without specifically providing results for BC. Concurrently, RV scanned reference lists of large centre studies (e.g., *n* = 300 or more) for articles that may have been missed in the initial search.

Data Extraction

Covidence allows for a pre-determined data extraction form to be applied to each article selected for full-text inclusion. Our data extraction included the following columns, representing the information extracted from each article: 1) author and study title, 2) region, 3) study aim and design, 4) population age and characteristics (e.g., cancer type, treatment type), 5) method of conception, 6) relevant outcomes, 7) additional notes. The synthesized data extraction table is displayed in the results section below (see Table 2).

Evidence synthesis in scoping review methodology has not been well articulated (Pollock et al,. 2021) but is generally summarized in themes. The current scoping review revealed three main themes as they related to evidence regarding ‘kids after breast cancer.’ The themes were: 1) recurrence rates, 2) pregnancy complications and outcomes, 3) Assisted Reproductive Technology (ART), and 4) postpartum outcomes (mainly associated with breastfeeding challenges) (summarized in Table 1). Limitations are discussed below.

Table 1

Scoping review themes with examples

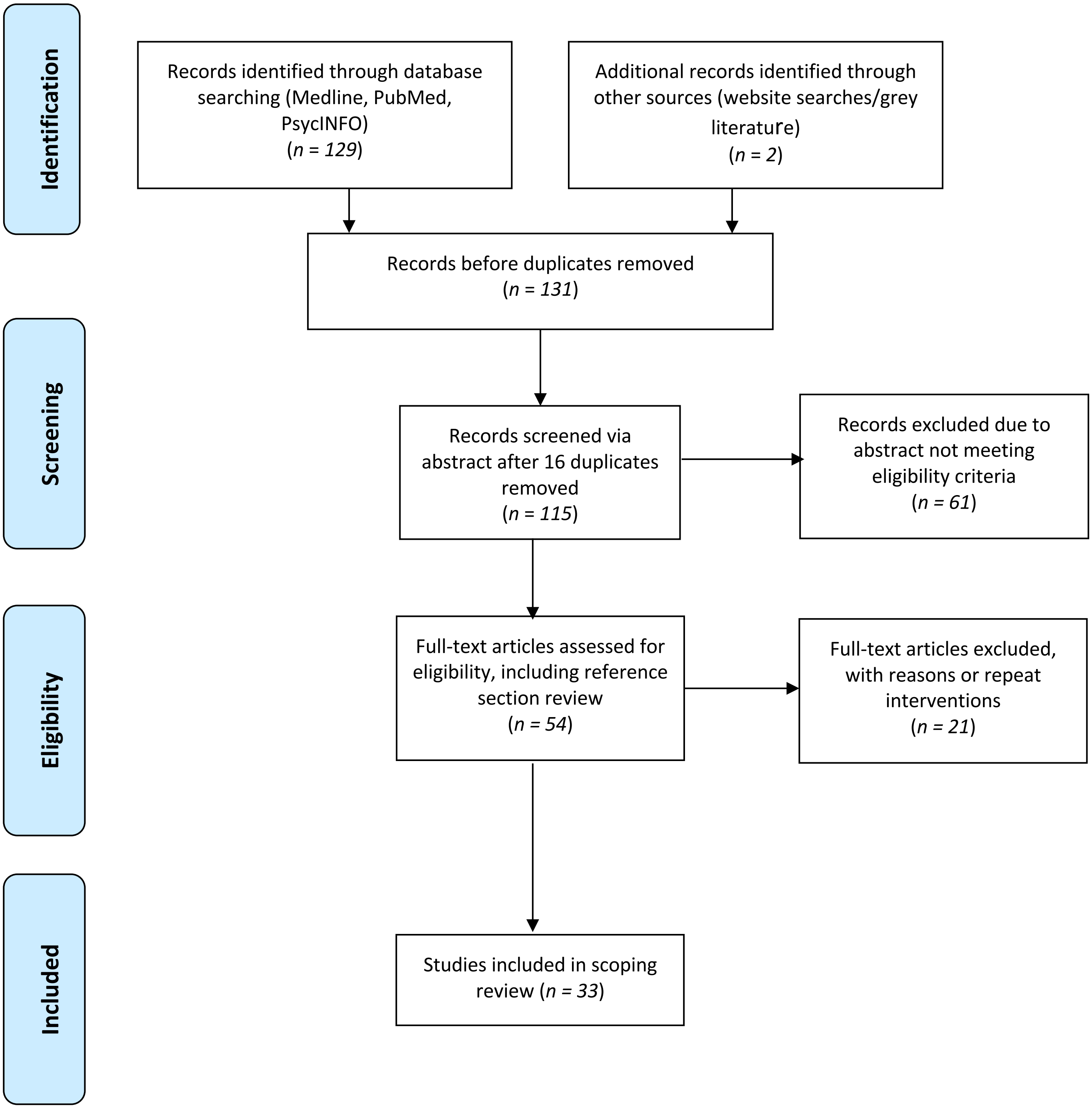
Themes	Theme examples
Recurrence Rates	Time to pregnancy Disease type (e.g., HR+) Use of ART
Pregnancy Complications/Outcomes	Use of ART Live birth Miscarriage Low birth weight Emergency C-Section Time to pregnancy BC treatment
Assisted Reproductive Technology	Safety for women with HR+ disease Safety for women with BRCA mutations
Postpartum/Breastfeeding	Safety of breastfeeding from treated breast (e.g., surgery, radiation) Screening considerations based on disease type (e.g., BRCA) Safety of screening options (e.g., Ultrasound, MRI)

Results

After screening the titles, 131 studies were imported to Covidence for abstract screening. Of those, 16 duplicates were removed. In total, 115 studies were screened for abstract by two members of the research team (RV and a research assistant), of which 61 studies were deemed irrelevant as they did not meet eligibility criteria. Fifty-four studies were included for full-text review, identified through database searches and grey literature searches. Each article was reviewed by the first author, 21 of which were excluded as they did not meet eligibility criteria or included overlapping data sets. In this case, the original article was retained. The final scoping review included 34 studies. See the PRIMSA flow diagram below (Figure 1), which illustrates the selection process. To help guide the development of a tailored resource to better inform stakeholders, we were interested in study outcomes that provide more nuanced context above and beyond the extant literature for sub-populations of YWHBC (e.g., ER+, BRCA carriers). Results were organized into four specific topics of interest, which included: 1) Assisted Reproductive Technology (ART) outcomes; 2) pregnancy incidence and outcomes; 3) breast cancer recurrence; and 4) postpartum period (screening and breastfeeding). Although there are various meta-analyses and systematic reviews published in the area of pregnancy after primary BC treatment, our review focused on synthesizing data that would be pertinent for specific sub-populations within the YWHBC community. The majority of studies (*n* = 13) related to pregnancy incidence and outcomes for YWHBC. Of note, many studies reported on multiple outcomes (e.g., recurrence rates, pregnancy outcomes). For the purposes of this analysis, studies were included only in the category that was the focus of the paper, rather than on secondary results. No studies reported novel secondary outcomes that were not already supported by other papers.

Figure 1

PRISMA flow diagram of phases of article selection



Assisted Reproductive Technologies (ART)

An important category included in our analysis was the safety of Assisted Reproductive Technologies (ART) (e.g., in-vitro fertilization) for YWHBC. Rates of fertility preservation are difficult to determine for YWBC as these statistics have not been historically recorded. However, studies report between 2-18% of women undergo gold standard fertility preservation (e.g., oocyte or embryo cryopreservation), while approximately 31-46% of patients are offered GnRH as a fertility preservation option prior to primary treatment (Greer et al., 2021; Mannion et al., 2024). Therefore, it is important to understand the safety and pregnancy outcomes for YWHBC who use ART, especially for women with hormone receptor positive disease who may worry about the impact of engaging in treatments that require an increase in hormones to attempt pregnancy.

In total, there were nine studies identified for extraction that reported on ART. In general, YWHBC were more likely to become pregnant and deliver when using donor oocytes versus autologous oocytes (Luke et al., 2016). Only one study specifically reported on the impact of GnRH on future pregnancies for women with ER+ and ER- disease (Wong et al., 2013). The median time to follow-up after the final goserelin (GnRH agonist) injection was 58 months, at which point 84% of participants had recovered menstruation. Ultimately, 71% of those participants achieved pregnancy after primary treatment, with no significant impact on pregnancy outcomes or recurrence.

Two of the studies were case studies, while the other seven were population-based cohort studies that employed retrospective analyses. The two case studies (da Motta et al., 2014; Muthuvel et al., 2018) included women who were ER+ and over 40 years of age at conception. One woman underwent IVF nine years after diagnosis, and one 6 years after diagnosis. Both women had received chemotherapy as their primary BC treatment. In both cases, there were no reports of adverse obstetric or fetal outcomes at the time of publication. However, both women delivered via c-section, which could indicate a higher risk delivery.

Both Rosenberg et al. (2019) and Ruah-Hain et al. (2023) found that fertility preservation does not impact the risk of recurrence, nor does undergoing fertility treatment (e.g., IVF) after primary BC treatment. Similarly, there does not seem to be any difference in the overall survival rates between women who undergo ART versus those who had a spontaneous pregnancy. However, there may be a higher rate of miscarriage for women who undergo ART (Ruah-Hain et al., 2023). That said, considerations should include age at initial conception as higher age is generally associated with an increase in miscarriage within the general population (Magnus et al., 2019).

Three studies (Sorouri, K et al., 2024; Wang et al., 2022; Marklund et al., 2021) showed that women were more likely to give birth if they had undergone fertility preservation before primary BC treatment, regardless of whether they had received chemotherapy. In addition, fertility preservation was associated with lower rates of miscarriage (as compared to YWHBC who did not undergo FP) (Wang et al., 2022). However, another study (Goldrat et al., 2015) reported on long-term outcomes of ART after BC, showing a higher rate of miscarriage for women who underwent ART, though no difference was observed in BC recurrence outcomes. This may be because Goldrat et al. (2015) included older aged participants (mean of 38.5 years) versus the mean age of 32 years reported for Wang et al. (2022). Excluding Goldrat et al. (2015), none of the other three studies found significant differences between groups when controlling for age, status and stage, ER and HER2 status, and BRCA 1 and 2 status. No significant difference in obstetric/neonatal outcomes or overall survival was observed between groups, though the fertility preservation group was significantly more likely to conceive compared to those who did not undergo fertility preservation prior to treatment. Women who undergo fertility preservation before primary BC treatment show a higher live birth rate post treatment and a slightly higher 5-year BC specific survival rate of 96.9% for women who underwent ART and 94.1% for women who did not (Marklund et al., 2021).

In general, ART appears to be safe for women with a history of BC, including those with ER+ disease, BRCA carriers, and regardless of primary treatment (e.g., chemotherapy, surgery, and/or radiation), as well as those who paused endocrine therapy to attempt pregnancy.

Pregnancy Outcomes

The majority of studies (n=13) identified for data extraction related to pregnancy incidence and outcomes. Although many of these studies also comment on risk of recurrence within the populations of interest, the main outcomes focused on rates of miscarriage, abortion, fetal abnormalities, and obstetric events (such as emergency cesarian sections, pre-eclampsia, and gestational diabetes). The following section further breaks down outcome data based on treatment and time to pregnancy - two of the factors discussed in the literature that may impact pregnancy outcomes.

Treatment Considerations

Surgery. One study (Alkhashnam, H. et al., 2020) specifically looked at the possibility of pregnancy after different methods of breast reconstruction[3]. The study demonstrated that pregnancy is possible after reconstruction, with some limitations. For example, while it is possible after transverse rectus abdominis muscle (TRAM) flap reconstruction, women should be

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[3] Common types of breast reconstruction for YWBC include implant and flap reconstruction. While implant reconstruction uses a foreign material such as silicone or saline, flap (TRAM or DIEP) reconstruction uses skin, fat, and sometimes muscle from another area of the body (National Cancer Institute, reviewed 2025).

counselled to wait one year after surgery to become pregnant due to the impact on abdominal muscles. However, DIEP flap surgery does not impact abdominal muscles and therefore is not contraindicated for pregnancy. In addition, dorsal and lower limb flaps have no consequence on pregnancy or labour.

Systemic Treatments. Treatments such as chemotherapy and radiation do not seem to significantly impact birth outcomes (e.g., miscarriage, spontaneous abortion), even in women with ER+ disease. However, chemotherapy shows an increased risk of adverse obstetrical outcomes such as lower birth weight and preterm birth (Bjelic-Radisic et al., 2020).

Overall, studies found that there was no increased risk of congenital abnormalities, gene disorders, or chromosomal syndromes after chemotherapy or radiation (Abel et al., 2021). However, there seems to be an increased risk of preterm birth, low birth weight, and low for gestational age for women who have a history of BC, specifically those with ER- disease who receive chemotherapy, either alone or in conjunction with other treatments (Abel et al., 2021, Anderson et al., 2018; Bjelic-Radisic et al., 2017). These risks were magnified for white mothers who gave birth within 2 years of diagnosis (Black et al., 2017).

Two studies found that it was safe for women to become pregnant after receiving adjuvant trastuzumab (Herceptin), often used to treat HER2+ BC. Both advised a minimum of 3-month washout period, after which there was no significant increase in pregnancy or delivery complications (Azim et al., 2012; Lambertini et al., 2019). However, trastuzumab during pregnancy is contraindicated and can cause serious fetal abnormalities such as Trisomy 21. Though there is no difference in disease free survival between pregnant and non-pregnant cohorts, pregnancy is less likely after trastuzumab treatment (Azim et al., 2012).

Three studies reported on pregnancy outcomes after tamoxifen treatment, specifically, interrupting tamoxifen to become pregnant (Partridge et al., 2023; Lewinsohn et al., 2024). One earlier study indicates that tamoxifen causes a high rate of severe congenital abnormalities, still birth, and spontaneous abortion if taken during pregnancy (Braems et al., 2011). While healthy pregnancy and birth has been observed, a 2-month washout period is recommended (Braems et al., 2011). Results of the POSITIVE study, a large trial reporting on the safety of pausing endocrine treatment to become pregnant (Partridge et al., 2023) demonstrated that tamoxifen cessation to pursue pregnancy is generally safe (though longer-term outcomes are needed as the medium time to follow-up was 3.4 years). The study collected pregnancy outcomes among 368 women who collectively had 507 pregnancies. Among the 507 pregnancies, 323 (63.7%) resulted in full-term live births, 27 (5.3%) in preterm live births, 114 (22.5%) in miscarriages or spontaneous abortions, 17 (3.4%) in elective abortions, 1 (0.2%) in stillbirth, and 1 (0.2%) in neonatal death; 20 (3.9%) were active (ongoing) pregnancies, and 4 (0.8%) had unknown outcomes. The rate of recurrence was similar for those who interrupted hormone therapy compared to those who did not. Similar results were found by Lewinsohn (2024) in a "real-world" study wherein the median time period for pausing hormonal treatment was 32 months and 23 months to delivery (i.e., 14 months from discontinuing hormone therapy to become pregnant). Of the 90 pregnancies recorded, 85 (94%) resulted in a live birth with no fetal abnormalities. At a 3.8-year follow-up, 40% of the sample had not resumed tamoxifen treatment. For those who resumed tamoxifen, median time to restart was 5 months postpartum. The study did not report on disease free survival. These results are important for healthcare providers to consider given that an increased number of women in the 'real world sample' (as compared to the POSITIVE trial) chose to forgo further treatment, motivated by perinatal considerations (e.g., future pregnancy attempts, breastfeeding). There is still more information needed in this cohort to better understand the outcomes of cycling between initiation and cessation of endocrine therapy as well as outcomes over a longer time period.

Time to Pregnancy. Two studies evaluated birth outcomes in relation to time to pregnancy from initial BC diagnosis (Jorgensen et al., 2022; Labrosse et al., 2021). One showed no statistical difference between women with a history of BC and controls in terms of preterm birth, smaller gestational age, maternal/neonatal morbidity (e.g., cardiac arrest, eclampsia, sepsis, shock), hypertension, gestational diabetes, renal disease, abnormal placentation, or chronic hypertension - though women with a history of BC were more likely to undergo Cesarian sections. In addition, chemotherapy did not modify any outcomes. Those who conceived 24-60 months after treatment had decreased odds of preterm birth as compared to those who conceived within 24 months post-treatment (Jorgensen et al., 2022).

The second study (Labrosse et al., 2021) specifically reported on time to pregnancy for women above the age of 35 with triple negative and HER2+ disease who received any combination of treatments. Although the majority of pregnancies were conceived naturally, some women became pregnant with ART (egg donation). Time to pregnancy was only significantly associated with endocrine therapy, given these patients often continue a 5–10-year course of endocrine treatment. Of the 197 pregnancies reported, 64% resulted in live birth and only 28 women experienced pregnancy complications. Complications included gestational diabetes, preeclampsia, hypertension, preterm birth, and intrauterine growth restriction. Additionally, data showed that late age pregnancy (over 40) and ART are not significantly associated with obstetrical or neonatal complications, though late age pregnancy is significantly associated with miscarriage. Of the 133 participants in this study, 22 women (16.54%) experienced recurrence over the course of the 12-year study period (Labrosse et al., 2021).

Cancer Recurrence

In total, five articles focused on different variables impacting recurrence for young women with a history of breast cancer (YWHBC) who gave birth after primary treatment, two of which were specific to BRCA 1 and 2 carriers (Lambertini et al., 2020; Lambertini et al., 2024). Overall, studies show that pregnancy after BC has no significant impact on disease free or overall survival rates for those who became pregnant versus those who did not, regardless of genetic mutations and ER+ disease.

In a secondary analysis of women with different cancer types (ER+, ER-), Anderson et al., (2022) found that overall survival increased for those who had a live birth, were nulliparous before diagnosis (i.e., no previous births), and gave birth within 5 years of diagnosis. In addition, women who had more than one birth showed similar survival rates to those who had no pregnancy. Effects for overall survival became insignificant for women who had a previous pregnancy or waited over 5 years from diagnosis to become pregnant. Additionally, ER+ status and chemotherapy treatment did not significantly impact risk of recurrence and survival. However, younger age at diagnosis (20-25 years old) as well as at least one live birth post-treatment showed a slightly higher survival rate as compared to those diagnosed at an older age (36-39 years old) who subsequently gave birth.

Lambertini et al. (2018) found that patients diagnosed with ER+ status BC who became pregnant showed no difference in disease free survival or overall survival compared to ER- patients. However, compared to their non-pregnant counterparts, ER- patients showed slightly better overall survival in the pregnancy cohort. In addition, abortion, time to pregnancy, and breastfeeding status had no impact on disease free survival, nor did adjuvant therapy for ER+ patients.

Lambertini et al., (2020, 2024) published two studies related to BRCA 1 and 2 carriers who became pregnant after primary BC treatment compared to their non-pregnant cohorts. Both studies found no adverse outcomes for BRCA carriers who gave birth, including those who were ER+. In addition, disease free survival was improved in the pregnancy cohort, which included both women who had an abortion and those who had a live birth. Thus, pregnancy, regardless of the outcome, may be protective.

Finally, Verkooijen et al. (2010) found that childbirth after BC treatment is correlated with a 14-fold increase in risk of death compared with the general population of women who gave birth. However, those with no childbirth show a 30-fold increase risk of death compared with the general population. At 10-years after diagnosis, all women with a history of BC showed similar mortality risk, regardless of whether they became pregnant. Interestingly, Verkooijen et al. (2010) report that women who gave birth over 4 years after diagnosis showed reduced mortality risk compared to those who gave birth within 2 years of diagnosis.

Each of these studies provide important insight into variables not previously examined in the literature such as the way pregnancy and childbirth interact with time from cessation of treatment to pregnancy, hormone status, and BRCA 1 and 2 carriers. In general, pregnancy appears to be safe for women with a history of BC, including those with ER+ disease and BRCA 1 and 2 mutations. These studies also suggest that YWHBC who become pregnant after primary BC treatment may have a higher relative disease free and overall survival period compared to their non-pregnant counterparts. However, the longest reported follow-up included in this scoping review was at 12-years, so more data are needed to better understand the extent of disease free and overall survival after pregnancy. Time to pregnancy (and pausing of hormonal therapy where relevant) may have implications in overall survival (e.g., waiting over 5 years before trying to conceive), though this area requires more data to better understand time to pregnancy within different sub-groups of women with a BC history (e.g., BRCA carriers).

Postpartum Considerations

In total, six articles were selected for extraction that focused on breastfeeding and screening considerations for women with a history of BC in the perinatal period.

Breastfeeding

Overall, breastfeeding is generally possible for women without a double mastectomy after primary BC treatment and does not seem to have any adverse outcomes on recurrence. Peccatori et al. (2020) noted the long-term considerations regarding the effects of both surgery and radiation on the mammary glands, such that lactation is dependent on the proximity of incision (e.g., areola and nipple), the location of the tumor, and the type of, and dosage of, treatment (e.g., radiation). Peccatori et al. (2020) report that up to 80% of BC patients treated with surgery and radiation subsequently experience less breast enlargement and engorgement while pregnant. In addition, 50% have limited milk production from the treated breast (Peccatori et al., 2020). Another study (Mitchell et al., 2019) reported that residual breast tissue may remain after surgery, leading to secretion that gives the appearance of typical lactation. However, the experience of significant lactation in this case may mean that there is an abundance of residual tissue, thus increasing the risk of recurrence. In such instances, the authors recommend that patients present to their healthcare team for further investigation.

One article (Moran et al., 2005) showed that lactation was still possible in the non-treated breast after surgery and radiation, and participants reported little to no swelling of the treated breast during pregnancy. Although women may produce some milk out of the treated breast during lactation if they are not taking pharmacological lactation suppressants, there is a high likelihood of diminished volume of breast milk. In rare cases, women may produce the same volume in both the treated and untreated breast (Moran et al., 2005). A common concern for patients is whether feeding from one breast will be a sustainable food source for their children (e.g., concern for volume of breast milk). In these cases, YWHBC should be counselled on the sufficiency of breast milk production from a single breast. In the case of feeding twins, Johnson & Mitchell (2020) state that a single breast can produce sufficient milk for healthy growth of an infant, and this is also true for YWHBC. However, when patients have more than one child (e.g., twin birth), providers should closely monitor both children to ensure each is receiving sufficient milk consumption for healthy growth and weight gain. Women may be encouraged to express milk in addition to breastfeeding in order to stimulate the breast to increase milk production. YWHBC who received both mastectomy and chemotherapy as their primary treatment may have reduced milk production in the unaffected breast and should also be closely monitored and counselled for supplemental feeding options, such as formula or donor milk (Johnson & Mitchell, 2020).

In one survey of breastfeeding women (Azim et al., 2010), 50% ($n = 10$) attempted to breastfeed. Reasons cited for stopping were pain, inability to latch, and insignificant milk production. For those that did not attempt to breastfeed, they were either counselled against it or did not have the option to breastfeed due to a double mastectomy. Azim et al. (2010) and Linkeviciute et al. (2020) both point to the fact that, while breastfeeding appears safe for YWHBC, and may even act as a protective factor against cancer recurrence, the lack of sufficient empirical information regarding breastfeeding, as well as inaccessibility to lactation consultants for many women result in decreased breastfeeding.

Screening

Ongoing cancer screening is also an important consideration for YWHBC. Mitchell et al. (2019) suggest that breast density may decrease screening test sensitivity and therefore, expression of milk is recommended prior to screening appointments to avoid false positive results. One important consideration is the safety of the type of screening (e.g., ultrasound, Magnetic Resonance Imaging (MRI)). Studies show that mammogram and ultrasound are both safe during lactation and YWHBC may continue lactation and feeding, even during routine screening. Other tests that use radiation for imaging do not appear to adversely impact breastmilk production or safety, including radiography, fluoroscopy, mammography, and CT scans. Therefore, none of these tests are contraindicated during lactation.

Two studies provided a breakdown of recommendations for specific screening tests (Johnson & Mitchell, 2020, Mitchell et al., 2019). Screening techniques that use intravenous contrast or gadolinium-based intravenous contrast (CT scans and MRI respectively) are considered safe, though the taste of breast milk may be altered (Mitchell et al., 2019). Thus, some women may decide to delay screening until they cease breastfeeding. However, the necessity of screening may depend on risk. For example, BRCA carriers are at higher risk of recurrence and should be counselled to continue screening throughout the postpartum period, even when breastfeeding. Both CT scans and MRIs are considered safe and thus there is no need to stop breastfeeding. Additionally, PET scans do not affect breast milk, but contact should be limited for 12 hours to allow radiation agents to dissipate. Patients should also be aware that breastfeeding alone changes the physiology of the breast (e.g., breast and areola enlargement, increase in breast density, and presence of nodules in the breast) and may reveal more false positives that require additional methods of discovery such as biopsy. Such decisions should be discussed on an individual basis to decide the best course of action dependent on BC history (Johnson & Mitchell, 2020; Mitchell et al., 2019).

Screening options also include supplemental imaging such as ultrasonography, which tends to offer the highest sensitivity and digital breast tomosynthesis ("3D mammography"), which is superior to conventional mammography. Again, women who present with a history of BC would benefit from consultation with a breastfeeding specialist to decide the course of action for screening depending on their personal breastfeeding goals and their risk factors (Johnson & Mitchell, 2020).

Studies have consistently shown that breastfeeding after BC is safe and does not increase the risk of recurrence (Blondeaux et al., 2024; Azim et al., 2024). However, certain medications prescribed to increase the production of breastmilk may negatively impact tumour growth and decrease the efficacy of adjuvant treatment such as endocrine therapy. For example, prolactin promotors (such as domperidone) may elevate prolactin levels leading to an increased risk of BC. Women with a history of total mastectomy (e.g., removal of 95% or more of the breast) should be advised to plan for breastfeeding with one breast (Mitchell et al., 2019).

In general, reduced milk production should be expected from the treated breast and is likely after treatments such as partial mastectomy and radiation. Specifically, radiation permanently alters breast tissue and thus the amount of milk produced. In addition, the taste of breast milk may be altered, leading to reduced feeding from infants. It should be noted that lactation from a radiated breast is not dangerous to the infant, but the breast tissue has reduced elasticity, and milk will not be as easily extracted (Johnson & Mitchell, 2020).

Finally, the safety of breast milk from women receiving tamoxifen is currently unknown. Aromatase inhibitors (hormone therapy used to treat BC) may impact the metabolism of estrogen in the infant such that breastfeeding is contraindicated. Currently, European guidelines support prolonged interruption of tamoxifen to allow for breastfeeding (Johnson & Mitchell, 2020).

Postpartum considerations for YWHBC are important to discuss during pregnancy, so women are appropriately counselled on their own individual expectations for breastfeeding (or formula feeding) and screening. The majority of the studies included cite the imperative for lactation specialists on multidisciplinary teams to help counsel YWHBC through breastfeeding. Generally, breastfeeding and screening is safe and possible for many YWHBC who have a live birth.

Discussion

The current study aimed to summarize empirical evidence regarding outcomes of assisted reproductive technology (ART), pregnancy, rates of recurrence, and breastfeeding and screening for YWHBC in the perinatal period. Given past research has focused more generally on the safety of pregnancy after BC, our aim was to amalgamate research that included interactions between specific variables of interest that have not been historically reported (e.g., disease characteristics, BRCA 1 and 2 mutations). Our hope is that this scoping review can begin to identify and fill gaps in the literature and, in doing so, help to equip patients and healthcare providers with better information for tailored decision-making and counselling for YWHBC in the perinatal period.

Of particular importance, one commonly cited concern for YWHBC is that they do not have access to tailored information to help them navigate the perinatal period (Vanstone et al., 2021). Not only does this informational gap significantly increase uncertainty, anxiety, and distress for this population (Martinez-Cannon et al., 2021), it may also adversely impact mental health outcomes. For example, young women show disproportionately elevated levels of fear of cancer recurrence (FCR) compared to their older cohort counterparts (Lebel et al., 2014). Further, FCR may be exacerbated in response to limited BC education (Liu et al., 2011) when patients engage in family planning (Arumand et al., 2018), during pregnancy (Azulay et al., 2020) and into the postpartum period (Vanstone et al., 2021). Such distress can lead to avoidance of mammograms, ultrasounds, and other forms of screening (Thewes et al., 2012), thus compromising physical health outcomes as well. While the safety of pregnancy and breastfeeding has been well established in the literature (Gerstl et al., 2018), to our knowledge the current study is the first to summarize outcomes relating to recurrence and pregnancy with consideration of specific disease characteristics (e.g., BRCA carriers), time to pregnancy, ART, breastfeeding and breast screening. These results are integral to counselling and informing YWHBC in the perinatal period.

The scoping review identified 34 studies related to the perinatal period after primary BC treatment. Given the significant gap in this area of research until recently, we hypothesized that our search would produce very few results. The number of studies meeting our criteria and representing a broad scope of considerations is a promising indication that more research is being dedicated to better understand health outcomes for YWHBC in the perinatal period. However, the initial phases of the scoping review revealed that the majority of research in this area remains focused on fertility concerns or BC diagnosed *during* pregnancy – rather than consequences that a history of BC has during the perinatal period. These results are perhaps unsurprising given that the current study's population remains quite niche, with only 4-8% of women able to achieve live birth after primary BC treatment (Bae et al., 2022; Lambertini et al., 2021). While these rates may be rising given medical advancements and increased consistency with fertility preservation pre-treatment (Marklund et al., 2021), YWHBC in the perinatal period still represent a small minority of women within the broader BC survivor population. Thus, it is reasonable to assume that research dedicated to better understanding recurrence and pregnancy outcomes for YWHBC is generally slower to develop given recruitment rates are likely low. Regardless, dedicated research for YWHBC in the perinatal period will help to decrease distress and improve quality of life into the survivorship period.

Our scoping review revealed four distinct areas of research for YWHBC: 1) Assisted Reproductive Technologies (ART); 2) pregnancy outcomes; 3) rates of recurrence; and 4) postpartum considerations such as breastfeeding and screening. The majority of studies chosen for review focused on pregnancy and birth outcomes and were published between 2018-2024, the oldest of which was published in 2005. In general, our results suggest that pregnancy for YWHBC is safe, even possibly acting as a protective factor, given the higher rates of disease free and overall survival for pregnancy cohorts as compared to matched YWBC who did not become pregnant. These finding seem to be consistent with previous research wherein studies have found that pregnancy after BC is generally safe (Gerstl et al., 2018). The current study adds to the more general findings, showing that the safety of pregnancy extends to women with hormone positive disease (Lambertini et al., 2018), and HER2+ disease (Azim et al., 2012), as well as patients with BRCA 1 and 2 mutations (Lambertini et al., 2024, Lambertini et al., 2023). Similarly, our scoping review found no observed likelihood of fetal abnormalities regardless of treatment type (chemotherapy, radiation) (Bjelic-Radisic et al., 2020), though rates of miscarriage were significantly correlated with increased maternal age (Labrosse et al., 2021). However, this finding is consistent with general population data, showing that advanced maternal age (35 years and over) increased the risk of miscarriage, health risks (e.g., pre-eclampsia), and fetal abnormalities (Frick, 2020).

Perhaps of particular interest, the scoping review revealed information regarding the implications of ART for YWHBC, including those with HR+. Fertility treatments remain a source of distress for young women who have been diagnosed with BC both before and after primary BC treatment (Hong et al., 2023). Our results indicate that the use of GnRH prior to BC treatment is promising in that the majority of patients recover menses, and go on to achieve pregnancy, with insignificant rates of relapse (Wong et al., 2013). Additionally, pre-treatment fertility preservation is associated with a significant increase in post-treatment births with no difference in recurrence rates (Wang et al., 2022; Marklund et al., 2021). Finally, post-treatment ART procedures (e.g., in-vitro fertilization, intra-uterine insemination, controlled ovarian stimulation, and egg donation) were shown to be safe with no significant difference in pregnancy outcomes or recurrence rates compared to patients who conceived naturally - including for women with HR+ disease (Marklund et al., 2021; Rosenberg et al., 2019; Goldrat et al., 2015). Further, time to pregnancy did not have a significant impact on birth outcomes or overall survival (Rauh-Hain et al., 2022). This area of research may be increasingly important for both patients and providers given that guidelines recommend waiting at least 2-years until attempting pregnancy after primary treatment (Nolan et al., 2022). These guidelines are based on recurrence for YWHBC, which is most likely to occur up to two years after diagnosis (Nolan et al., 2022). Additionally, women with HR+ disease may require additional hormone treatments, which can extend 5-10 years past primary treatment, thus significantly prolonging time to pregnancy (Partridge et al., 2023). For many YWHBC relying on ART to become pregnant, these data may offer hope.

One surprising finding in the literature was the impact of breast reconstruction on pregnancy. Interestingly, certain types of breast surgery and reconstruction may impact the possibility of conception (Alkhashnam, H. et al., 2020). This is of particular importance as most YWBC will undergo surgery, likely in conjunction with additional treatment such as radiation or chemotherapy (American Cancer Society, 2021). For example, for women who undergo TRAM flap reconstruction, entailing removal of a portion of the rectus abdominis muscle for breast reconstruction, a one-year delay to pregnancy is recommended given the weakening of the abdominal wall and possible adverse effects during pregnancy (Alkhashnam, H. et al., 2020). Additionally, for women who receive an implant or expander-based reconstruction, MRI is contraindicated due to metallic tissue expanders (Alkhashnam, H. et al., 2020). Thus, YWHBC who are entering into the perinatal period must consider screening alternatives. Such information is integral to communicate to YWHBC who may be planning to become pregnant soon after surgery or when considering breast reconstruction.

Perhaps one of the most anticipated studies in the field was the POSITIVE study (Partridge et al., 2023), which showed that pausing hormone therapy for women diagnosed with HR+ BC does not significantly increase recurrence and shows no adverse pregnancy outcomes when compared with controls. The study included women with a median age of 37 years and a median of 29 months of tamoxifen treatment. Similarly, a study by Lewinsohn (2024) presented preliminary results of a ‘real world’ sample of YWHBC who ceased endocrine therapy to become pregnant. Lewinsohn (2024) similarly found no significant differences in recurrence or pregnancy outcomes. However, this study did report fewer participants re-starting endocrine therapy after giving birth.

Both of these studies are significant in being able to counsel women who wish to become pregnant after primary BC treatment but who require hormone therapy to reduce their risk of recurrence. As past research has shown, receiving 5 to 10 years of adjuvant endocrine therapy (Tamoxifen) after primary BC treatment significantly reduces rates of recurrence for young women with HR+ BC (Burstein et al., 2016). However, animal studies and case studies have revealed that endocrine therapy is contraindicated during pregnancy as it has adverse fetal and maternal outcomes (Braems et al., 2011). Deciding to delay pregnancy in favour of endocrine therapy may constitute a difficult decision for YWHBC, as they must decide between pursuing family building goals and lowering their chances of recurrence. While it may seem an easy decision, delaying pregnancy may increase distress and depression in YWHBC (Kitano et al., 2019) and some women may choose to prioritize their family building goals over potentially lifesaving treatment (Partridge et al., 2023). These studies give important insight into patient priorities after primary BC treatment and can help to guide both patients and providers in navigating the post-treatment period. The POSITIVE study again shows promising results that women may not need to delay pregnancy for significant periods of time without compromising their health outcomes in favour of pregnancy. However, Lewinsohn’s work (2024) suggests that fewer women resumed endocrine treatment after completing pregnancy, as compared with the POSITIVE trial results. This may be due to their wishes to breastfeed or pursue further pregnancies. More research is needed to better understand the long-term impacts of treatment cycling and the use of short-term endocrine treatment (e.g., 2 years vs 5 years vs 10 years) to bolster patient care in this area.

Finally, two papers provided guidelines for screening and breastfeeding after BC treatment. Mitchell et al. (2019) and Johnson and Mitchell (2020) published guidelines on screening and breastfeeding after primary BC treatment, showing that many screening techniques are safe for YWHBC who are either pregnant or breastfeeding. This information is particularly important as many current guidelines recommend waiting to receive routine screening until after delivery or delaying screening until women complete breastfeeding (Cancer Care Ontario, 2024). However, delaying screening may put some women at increased risk of recurrence. For example, BRCA carriers should be closely monitored given their high risk of recurrence as compared to women without a BRCA mutation. A recent study advises against delayed screening for pregnant and postpartum BRCA carriers, even amidst screening challenges such as altered breast tissue (Sorin et al., 2024). Although the study was not focused on YWHBC, it stands to reason that those with a BC history would follow similar guidelines. Johnson and Mitchell (2020) also address the possibility and safety of breastfeeding from a treated breast, which may be possible. Additionally, for women who are unable to breastfeed, they may still experience colostrum secretion, which can be worrying for those who have been told they were unable to produce milk. While screening and breastfeeding after primary BC treatment represent a significant gap in the extant literature for YWHBC, these studies provide excellent insight into understanding and properly counselling YWHBC on such issues.

Limitations and Future Directions

The current study has several limitations that are important to consider. Perhaps one of the most important is the quality of data included in the scoping review. While it was not within our study parameters to evaluate study and thus data quality, it is important to note that the majority of studies reported on retrospective or secondary data (e.g., from national databases). While such data are certainly valuable, it is difficult to make definitive statements regarding recurrence and pregnancy outcomes for YWHBC without prospective cohort study data.

Similarly, several studies reporting on individual characteristics (e.g., BRCA carriers, HR+ outcomes) comprise similar datasets and were published by the same research group. Future reviews will benefit from drawing data from multiple datasets and research groups so as to better understand these outcomes found in diverse populations.

Another important factor to consider for future studies is the relative paucity of data on outcomes for women of diverse, non-White, backgrounds, socioeconomic status, and gender identity. For example, young black women (ages 20-39) are more likely to be diagnosed with advanced breast cancer as compared to people of other races and tend to have worse outcomes. Similarly, women of lower socioeconomic status (SES) are less likely to have access to consistent healthcare and, thus are more likely to be diagnosed with later stage disease (Yedjou et al., 2020). Additionally, poor pregnancy outcomes are more common for racialized and lower SES populations in both Canada and the United States, particularly for Black women (e.g., low birth weight, pre-term birth, and late or no prenatal care) (Maxwell et al., 2024). Thus, better understanding the outcomes and needs for diverse YWHBC populations who become pregnant are integral for improving care. While the available data may be applied broadly, it will be important for patients and providers to better understand individual risks for diverse cohorts of YWHBC and whether demographic variables contribute to pregnancy outcomes and recurrence risks. Finally, as more data are collected, it will be useful to report on longitudinal outcomes, as many studies included in this review do not report on outcomes over 5-10 years after primary BC diagnosis. Better understanding the long-term impacts of ART, pregnancy, and breastfeeding on recurrence rates will help to inform counselling and decision making for YWHBC.

One area revealed to be under-researched as a result of our search is the topic of high-risk pregnancy after BC treatment. For example, it is well established that chemotherapy treatments, radiation, and adjuvant treatments, such as trastuzumab increase the incidence of cardiotoxicity for young female cancer survivors (of varying disease sites) (Bansal et al., 2022). For YWHBC who experience cardiotoxicity throughout treatment, the risk of cardiovascular events increases in pregnancy (Bansal et al., 2022). Thus, it is imperative that such considerations are explicitly stated prior to conception and that women with high cardiovascular risk are followed by a multidisciplinary team. As women transition out of primary cancer care and have reduced frequency of contact with their oncology team, they may experience significant gaps in care that evoke psychological distress. In fact, young women transitioning out of cancer care after BC treatment cite feelings of fear and anxiety due to unmet informational needs regarding hormonal therapies, cancer recurrence, and social support resources (Parker et al., 2023). Thus, bridging gaps in care should be of high priority, specifically for YWHBC who have been cancer-free for over 5 years, and may not have the continuity of care necessary for a safe pregnancy.

Overall, tailored care is lacking for YWHBC, and published guidelines do not consider the impact of adjunct treatments, screening, ART for women with hormone sensitive disease, BRCA carriers, and age ranges. The complex interaction between BC history and pregnancy introduces a wide range of questions and concerns for YWHBC as they enter the perinatal period. Historically, a very small population, there are gaps in knowledge in this area, limiting healthcare providers' ability to counsel patients. Fortunately, this research area is one that has seen promising growth over the past decade and continues to produce important research. At a recent conference, ESMO Congress 2024 (13-17 September), researchers presented on the safety of breastfeeding for BRCA carriers (Blondeaux et al., 2024) and HR+ patients who interrupted tamoxifen therapy (Azim et al., 2024). While exciting, it is important to widely disseminate such findings so that stakeholders can readily access such information. For example, patients may use such evidence to better understand their health and make choices about treatment continuation, body changes, and breastfeeding. Healthcare providers can use this information to provide guidance to their patients, as well as other providers. Previous research has found that many providers do not feel comfortable broaching the subject of pregnancy after BC treatment given their lack of knowledge about the topic (Warner et al., 2016). Although it is responsible to not counsel patients with insufficient information, this leaves YWHBC with limited access to trusted healthcare providers who can answer their complex questions and address their needs pertaining to pregnancy after BC.

Conclusion

Our scoping review was important in identifying and synthesizing available data regarding the perinatal period after primary BC treatment. Our hope is that this review adds additional context to the extant literature, addressing considerations such as treatment type, recurrence risk based on disease type, and breastfeeding and screening outcomes. Currently, patients report scarce informational resources, which they cite as a source of distress leading up to and during the perinatal period (Vanstone et al., 2021). All of the studies identified for extraction offered nuanced information on perinatal outcomes for YWHBC and were ultimately identified in order to inform the development of an online educational tool which is intended to support a more tailored approach to care and bolster patient empowerment and communication between stakeholders. Additionally, better understanding of these gaps may pave the way for tailored hospital and community programs to better address the needs of this population.

Table 2

Synthesized results table of perinatal and recurrence outcomes for YWHBC

Study, Setting & Sample Size	Cancer Type & Mean Age	Treatment Type	Conception Method	Study Type/Outcomes	Pregnancy Complications And/or birth abnormalities
ART					
da Motta et al., 2014 Brasil n=1	ER+ 41 years(at conception)	Chemotherapy	IVF	Case study 2 rounds of IVF with no reported recurrence. Resulted in live birth by c-section	None reported
Goldrat et al., 2015 Belgium n=25	ER+ HER2+ 38.5 years	Mastectomy Breast conserving Chemotherapy Endocrine therapy	Oocyte donation: Ovarian stimulation for IVF Ovulation induction:	Multicentre retrospective At 8.5 year follow-up no significant difference in recurrence between ART and spontaneous pregnancy	Higher rate of twin births and miscarriage with ART
Luke et al., 2016 USA n=441	Mixed sample with outcomes specific to BC 33.4 years	Not specified	IVF	Population based cohort study More live births were reported for women using donor oocytes versus autologous oocytes	None reported
Marklund et al., 2021 Sweden n=425	ER+ 32.1 years	Chemotherapy Other not specified	Transfer of frozen/thawed embryos or donor oocyte	Retrospective cohort study Live birth rate higher for women with fertility preservation (22.8% of sample) All-cause mortality lower in pregnant cohort at 5.8 year follow-up	3 preterm births
Muthuvel et al., 2018 n=1	ER+ HER2+ 42 years(at conception)	Surgery Chemotherapy Hormone therapy	IVF (oocyte donation)	Case study IVF resulted in live birth by c-section	None reported
Rauh-Hain et al., 2022 USA n=553 (pregnant)	ER+ PR+ ERBB2+ Triple Negative	Lumpectomy Mastectomy Radiation Chemotherapy	Controlled ovarian stimulation Fresh and frozen embryo transfers	Population-based cohort study	Higher rates of miscarriage

n=189 (ART)	32 years (spontaneous pregnancy) 35 years (ART)			Pre-treatment fertility preservation does not impact recurrence No difference in OS between YWHBC who undergo ART vs. spontaneous pregnancy OS similar for time to pregnancy, stage and type of cancer	
Rosenberg et al., 2019 Sweden n=37 (ART) n=148	ER+ PR+ HER2+ 32.5 years (at diagnosis)	Not specified	Pre-treatment FP IVF	Retrospective cohort study No relapses for women with IVF births	None reported
Wang et al., 2022 Canada n=71	ER+ PR+ HER2+ BRCA 1 and 2 32 years	Chemotherapy Radiation GnRH	Pre-treatment FP Controlled ovarian stimulation (IVF)	Retrospective cohort study	Rate of miscarriage significantly higher in non-FP 1 still birth
Wong et al., 2013 UK n=132	ER+ ER- 35 years	GnRH Chemotherapy	GnRH	Prospective cohort study 71% of sample achieved pregnancy No pregnancy complications reported Only one patient experienced relapse after pregnancy	None reported
Pregnancy Outcomes					
Abel et al., 2021 USA n=181	ER+ HER2+ Triple Negative BRCA 32.8 years (natural) 34.6 years (ART)	Chemotherapy	Spontaneous ART (IUI, FET, Donor)	Prospective cohort study Treatment does not significantly impact pregnancy outcomes	Reported instances of: Intrauterine growth restriction Gestational diabetes and hypertension Pre-eclampsia C-section
Alkhashnam, H. et al., (2020) France	Not specified	Breast reconstruction	Not specified	Review Pregnancy is possible after breast reconstruction Suggested 1 year delay after TRAM flap	None reported
Anderson, C et al., (2018)	ER+ ER-	Surgery Chemotherapy	Not specified	Population based study – secondary analysis	Pre-term births

USA n=4, 978	35.1 years	Radiation Radiation and chemotherapy Endocrine therapy		ER- disease more likely to be pre-term and low birth weight ER+ have lower pregnancy rates at 5 but not 10 years	Low birth weight Small for gestational age C-section
Azim et al., (2012) Belgium n=33	HER2+ 34 years	Chemotherapy Trastuzumab	Not specified	Randomized trial Pregnancy safe after cessation of Herceptin. More data necessary regarding infant cardiac profile	Spontaneous abortion One congenital abnormality reported
Bjelic-Radisic et al., (2020)	N/A	N/A	N/A	Review Chemotherapy does not have adverse affect on pregnancy outcomes Women may be at higher risk for obstetric outcomes	Low birth weight Preterm birth
Black et al., (2017) USA n=512	Not specified 31.8 years (at diagnosis)	Chemotherapy	Not specified	Retrospective population-based analysis Increased risk of preterm birth, low birth weight, and small for gestational age related to chemotherapy and birth within 2 years of diagnosis date Interaction between BC history and race significant for low birth weight and small for gestational age	Preterm birth Low birth weight Small for gestational age
Braems et al., (2011) Belgium n=11	ER+ Age not specified	Tamoxifen	Not specified	Retrospective analysis Tamoxifen taken during pregnancy causes high rate of severe congenital abnormalities. Washout period of 2 months	Multiple malformations Stillbirth Anorectal anomaly Diaphragmatic hernia
Jorgensen et al., (2022) USA n=553	Not specified 36 years (at time of delivery)	Not specified	Not specified	Population based study No statistical difference in terms of pregnancy complications or obstetric outcomes. Conception over 2	Preterm birth Smaller gestational age Maternal morbidity Hypertension

				years after BC diagnosis may decrease odds of preterm birth BC history more likely to have c-section	Gestational diabetes Renal disease Abnormal placentation Chronic hypertension
Labrosse et al., (2021) France n=133	Triple negative HER2+ 36.8 years (at first pregnancy)	Surgery Chemotherapy Trastuzumab Endocrine therapy	Spontaneous ART (egg donation, frozen oocytes, IVF)	Retrospective analysis Only endocrine therapy significantly associated with time to pregnancy (61 month average) Late age pregnancy and ART not associated with adverse obstetric or neonatal outcomes	Gestational diabetes Pre-eclampsia Hypertension Preterm birth Intrauterine growth restriction C-section Miscarriage
Lambertini et al., (2019) Belgium n=92	HER2+ 33 years	Trastuzumab	Not specified	Randomized trial No pregnancy/delivery complications reported No difference in disease free survival	One instance of Trisomy 21 (elective abortion)
Lewinsohn, R (2024) USA n=71	ER+ 33 years(at diagnosis)	Endocrine	Not specified	Population based secondary data analysis No adverse effects for those who paused endocrine treatment 40% of sample chose to forgo further treatment	None reported
Partridge et al., (2023) USA n=497	ER+ 37 years	Tamoxifen (3 month washout)	Natural ART	Single group trial Pregnancy is safe after endocrine treatment. No significant increase in recurrence	Preterm birth Miscarriage One stillbirth One neonatal death
Sorouri, K et al., (2024) USA/Canada n=197	ER+ BRCA 1 & 2 32 years (at diagnosis)	Chemotherapy Endocrine therapy Fertility preservation at diagnosis (egg/embryo cryopreservation)	Not specified	Multicentre prospective cohort study Greater age at diagnosis negatively associated with pregnancy Pre-treatment FP associated with higher pregnancy rates	None reported
Recurrence					
Anderson et al., 2022 UK N= 5, 181 (290 live births)	ER+ ER- Unknown 31 years	Chemotherapy	Not specified	Population based secondary analysis Overall survival increased for patients with live births, who	None reported

				were nulliparous, and gave birth within 5 years of diagnosis ER status had no significant impact 290 live births (5.7%)	
Lamertini et al., 2018 Belgium n=333	ER+ ER- Age not specified	Not specified	Not specified	Multicentre case control No difference in DFS or OS for ER+ vs. ER-, live birth vs. abortion, time to pregnancy, or breastfeeding status	None reported
Lambertini et al., 2020 Italy n=195	BRCA 1 BRCA 2 BRCA 1&2 ER+ HER2+ 35.7 years (at diagnosis)	Surgery (conserving, radical) Chemotherapy Endocrine	Spontaneous ART	Multicentre retrospective cohort study DFS improved in pregnancy cohort Pregnancy appears safe for women with BRCA mutations, including those with ER+ disease	Miscarriage Pre-term birth Delivery complications Congenital abnormalities
Lambertini et al., 2024 Italy n=659	BRCA 1 BRCA 2 BRCA 1&2 ER+ HER2+ 34.7 years (at diagnosis)	Surgery (conserving, radical) Chemotherapy Endocrine	Spontaneous ART (embryo transfer after cryopreservation, after donation, ovarian stimulation for IVF or ICS)	Multicentre retrospective cohort study More than 1 in 5 BRCA carriers became pregnant DFS comparable with non-pregnant matches	Miscarriage Preterm birth Pregnancy complications Delivery complications Congenital abnormalities
Verkooijen et al., 2010 Sweden/Singapore n=492	ER+ ER- 32 years (at diagnosis)	Chemotherapy Tamoxifen	Not specified	Population based secondary data analysis Pregnancy after BC lowers risk of death (compared to general population) After 10 years, mortality rate for those who gave birth and those who did not were comparable	None reported
Postpartum Outcomes					
Azim et al., 2010 Italy n=20	ER+ HER2+ 36 years (at delivery)	Breast conserving surgery Radiation Chemotherapy Hormonal therapy	Not specified	Retrospective cohort study 50% of sample attempted	None reported

				breastfeeding. No recurrence reported Breast feeding ceased due to mastitis and reduced milk production	
Johnson et al., (2020) USA	Not specified	Not specified	Not specified	Review and guidelines Breastfeeding does not increase rates of recurrence Variety of screening tests safe when breastfeeding Reduced milk production is likely with partial mastectomy and radiation	None reported
Linkeviciute et al., (2020) Italy	Not specified	Not specified	Not specified	Review and guidelines Breastfeeding is not associated with recurrence or new disease Majority of YWHBC do not breastfeed due to physical, psychological, and social barriers	None reported
Mitchell et al., (2019) USA	Not specified	Not specified	Not specified	Review and guidelines Breastfeeding does not increase rates of recurrence Variety of screening tests safe when breastfeeding Reduced milk production is likely with partial mastectomy and radiation	None reported
Moran et al., (2005) USA n=21	Not specified 32 years (at diagnosis)	Breast conserving surgery Radiation Chemotherapy Tamoxifen	Not specified	Retrospective secondary analysis Lactation was observed in 10 treated breasts but milk production was generally decreased	None reported
Peccatori et al., (2020) Italy	Not specified	Chemotherapy Radiation Endocrine therapy	Not specified	Review YWHBC treated with breast conserving surgery and radiation	None reported

				experience diminished breast enlargement and engorgement during pregnancy. Milk production is generally decreased but breastfeeding appears safe for YWHBC	

Chapter 3

Study 2 – An Examination of Patient, Provider, and Community Partner Perspectives of the Perinatal Period After Breast Cancer: A Thematic Analysis

Introduction

As of 2023, breast cancer (BC) was the highest funded cancer subtype globally (McIntosh et al., 2023). This allocation of funds is due to several reasons including the prevalence of individuals impacted by BC, the cost of BC treatment, and the impact of screening. While survival rates have increased due to improved screening programs and medical advancements, the number of young women with breast cancer (YWBC) has increased more than 2% annually over the past 5 years (Breast Cancer Research Foundation, 2024). In fact, BC is the most commonly diagnosed cancer for women of reproductive age (Sorouri et al., 2024). The increase in BC diagnoses for young women is particularly concerning due to the unique diagnostic considerations for this population, including more aggressive disease characteristics (e.g., human epidermal growth factor receptor 2 (HER2+)), genetic risk factors (e.g., BRCA 1 and 2), and advanced disease at diagnosis (e.g., larger tumour size, advanced tumour stage) (Xu et al., 2024)[4].

Another important consideration for YWBC is their unique survivorship goals that differ from older BC cohorts. Namely, fertility preservation and pregnancy considerations are cited as a topmost concern, given that many YWBC will not have yet fulfilled their family building goals (Hu et al., 2019). Early discussions with YWBC regarding family building become imperative for women who plan to become pregnant after primary treatment given that the majority of

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[4] Studies suggest that poorer prognosis for YWBC may be due to limited screening available for younger populations, dismissal by healthcare providers (e.g., symptom presentations believed to be due to other causes), and missed symptoms by patients (Costa et al., 2023).

standard BC treatments have adverse implications for reproductive health. Such treatments may impact ovarian reserve, cause early menopause, and introduce time delayed childbearing, and breastfeeding challenges (Shah et al., 2019)[5]. Thus, discussions with YWBC regarding fertility and family building goals have become a standard of care. For example, international guidelines recommend that healthcare providers initiate conversations regarding the impact of cancer treatment on fertility with each patient treated 'during reproductive years' and as early as possible after BC diagnosis and be prepared to refer them to fertility specialists prior to treatment (Cardoso et al., 2024). Oktay et al. (2018) note that fertility preservation techniques such as sperm, oocyte, and embryo cryopreservation are currently considered to be standard practice according to the American Society of Clinical Oncology and are widely available. In addition, gonadotrophin-releasing hormone agonists (GnRHa), which induce ovarian suppression during treatment should always be offered to patients as they reduce the chance of chemotherapy-induced ovarian reserve reduction (Oktay et al., 2018).

Despite these guidelines, YWBC consistently report a lack of information regarding fertility and pregnancy both prior to and after the conclusion of primary BC treatment (Ameri et al., 2018; Azulay et al., 2020). The lack of communication and information sharing is often due to limited healthcare provider knowledge regarding fertility preservation options and pregnancy guidelines, and some cases wherein providers do not consider fertility and pregnancy in the purview of their care (Warner et al., 2016; Zhang et al., 2019). Unfortunately, poor communication may have practical implications for YWBC. For example, one study showed that, at time of diagnosis, 57% of survivors reported concerns regarding infertility due to treatment, and 29% reported making treatment decisions based on fertility concerns (Taylor &

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[5] See Chapter 1 and 2 for in-depth discussion of treatment impacts and fertility considerations.

Meisel, 2021). Understandably, without sufficient information to help plan for family building after BC treatment, YWBC may experience increased distress as they shift focus away from treatment decisions to longer-term survivorship. In fact, it is well documented that YWBC experience significantly more distress after primary BC treatment compared to their older counterparts, including anxiety, depression, and body-image concerns (Goerling et al., 2020). YWBC also report heightened distress when engaging in family planning (Arumand et al., 2018) and during pregnancy (Azulay et al., 2020), consistently citing an increased need for health information and psychological support (Goerling et al., 2020). Studies show that clear and comprehensive information sharing helps to reduce psychological distress (Mahajan et al., 2015). Therefore, there is an urgent need to bridge this gap in care in order to support young women with a history of breast cancer (YWHBC) well into survivorship. This responsibility should not only fall on the patient population but include their circle of care.

Guidelines for Fertility and Pregnancy

Although increased distress due to lack of information is well established in the empirical landscape, YWBC continue to be underserved in terms of specific and practical tailored care. Paluch-Shimon et al. (2020) report a consistent lack of evidence-based standards and guidelines to help guide YWBCs' fertility and pregnancy decisions from the beginning of BC treatment through to survivorship (e.g., resources for BRCA carriers, best treatments to support family building goals, and follow-up care). However, supportive care is imperative for YWBC psychological wellbeing. Studies cite that supportive care for YWBC should include access to innovative services such as personalized psychosocial support, counseling on genetic mutations, and fertility. Further, they cite the need for "innovative and structured communication and supportive tools," (Paluch-Shimon et al., 2022, pp. 1099) such as online programs and support groups, which help increase positive physical and psychological health outcomes (Paluch-Shimon et al., 2022). Given that YWBC are at higher risk for psychological distress compared to their older counterparts, continued psychosocial support and supportive care follow-up with YWBC becomes necessary during and following treatment to help manage distress related to family building.

While slow moving to implement, guidelines to support YWBC into the survivorship period have been developed (Runowicz et al. 2016). Such guidelines are meant to enhance the quality of clinical care follow-up by providing recommendations for healthcare providers who have contact with YWHBC after primary BC treatment. For example, recommendations include involving multidisciplinary teams in potential discussions related to pregnancy after BC treatment (e.g., medical oncologist), and timelines for referrals to fertility specialists (YWHBC who have attempted conception for 6 months or more or who have had one or more miscarriages) (Runowicz et al. 2016). While useful for providers, these guidelines focus solely on fertility and the process of *becoming* pregnant, rather than on considerations for care during the perinatal period (conception to 5 years postpartum). Although they are a necessary first step for women hoping to conceive, these guidelines are not adequate in supporting YWHBC (or those in their circle of care) who are currently navigating the perinatal period (conception to 5 years postpartum).

Supportive Care for YWBC

Supportive programming is another domain that remains underdeveloped for this population. One recent study exploring the domains of support for this population noted that both academic (e.g., hospital programs) and community setting (e.g., support groups) offer supportive resources for YWBC (e.g., cancer support groups, exercise programs) (Yufe et al., 2025).

However, while both avenues continue to expand access to support throughout the cancer trajectory into the survivorship period, gaps in care were still identified (Yufe et al., 2025) and may leave YWHBC without adequate support to address specific needs related to the perinatal period. Although a small percentage of BC survivors will go on to become pregnant (3-8%) (Lambertini et al., 2021), resources to navigate the perinatal period are necessary. Available research has focused on the general safety of pregnancy after cancer treatment (Gerstl et al., 2018) but YWHBC still cite the lack of information and support addressing considerations specific to their individual needs (Vanstone et al., 2021). For example, considerations such as coming off endocrine therapy to become pregnant, how long to wait to attempt pregnancy based on type of cancer (ER+, ER-) and screening considerations for BRCA 1 & 2 carriers are questions often left unanswered for patients and providers alike. Additionally, providers cite lack of knowledge in this area and may avoid giving advice or asking about the perinatal period as they do not have the foundation of knowledge necessary to counsel women about decisions and outcomes related to the perinatal period (Khan et al., 2022; Warner et al., 2016). For example, Khan et al. (2022) found that 57.6% of medical oncologists working in an academic setting disagreed or were unsure whether ovarian stimulation was considered safe for YWHBC. Furthermore, there are few support programs that are geared directly toward YWHBC who are in the perinatal period (personal communication with Rethink Breast Cancer and Gilda Club community organization representatives, 2023). Understandably, providers' trepidation to discuss the perinatal period, combined with limited access to support programs may further exacerbate distress and concern for YWHBC. Therefore, increased understanding and resource development in this area are warranted.

Importance of Knowledge Translation After Breast Cancer Treatment

In addition to easing psychological distress for YWHBC, there has been increased attention paid over the past decade to person centred care and patient empowerment within healthcare settings (Hickmann et al., 2022). Research shows improved health outcomes for patients who are engaged in their own care and collaborate with healthcare providers (Paterick et al., 2017; Hickmann et al., 2022). In addition, having continuity of terms and information for both patient and provider helps to improve communication, which may lead to stronger adherence to medical advice (Hickmann et al., 2022). One study showed that interventions focused on patient and provider empowerment are associated with improved clinical outcomes (e.g., reduced postoperative pain) and improved quality of care from healthcare providers (Bailo et al., 2019). Avenues to improve patient empowerment can be gained through skills development, and access to information and resources that may impact treatment decisions and health in general (Bailo et al., 2019).

Therefore, having active control in the healthcare processes may be integral for patient health outcomes. As Bailo et al. (2019) state of patients' cancer experience, "since patients do not have direct control over their condition, they need to be actively engaged to access different information sources and to relate with people involved in the care process…" (pp. 2). Ensuring that patients have control over their treatment decisions may also lead to improved psychological outcomes for YWHBC. Such outcomes may include positive experiences with healthcare, improved self-management strategies and health behaviours, and better clinical outcomes as a result of information access (Bailo et al., 2019). One study cited that knowledge gathering is a crucial skill that not only helps to empower patients but is highly correlated to healthcare providers' ability to provide and clearly explain health related knowledge such as treatment options and consequences to their patients (Kondylakis et al., 2014).

Supportive care is integral both throughout and after primary treatment when patients may need to engage in certain lifestyle changes and health behaviours to bolster the effects primary treatment (e.g., exercise programs, diet management, adjuvant therapies) (Schmidt et al., 2022). Engagement in care becomes of particular importance as YWHBC navigate the perinatal period, which may directly interfere with secondary cancer treatments (e.g., endocrine therapy).

Given the increased psychological burden due to disrupted life trajectories, and the paucity of information regarding fertility and pregnancy for YWHBC, resource development is imperative in helping to support YWHBC into the survivorship period and in bolstering health outcomes. Doing so not only involves equipping patients with reliable supports and resources but also members of their circle of care, which may include both healthcare providers and community supports (e.g., survivorship support groups). Further, patient engagement in resource development contributes to more appealing formats for educational materials and design that fits participant needs. Such resources have been shown to build trust in online content and increases the likelihood for targeted users to access such resources (Lewis et al., 2024).

Current Study

Given the lack of information and resource access available to patients, and the hesitation of resource sharing for those in their circle of care, our aim was to better understand common questions, concerns, and extant knowledge that stakeholders have regarding the perinatal period after BC. Along with patient and healthcare provider perspectives, we were also interested in including community partners who have direct contact with YWHBC and are involved in developing accessible supportive care programs. As such, these three participant groups were included in our sample. To best capture participant perspectives, we chose to conduct a thematic analysis with patient, healthcare provider, and community partner participants, which included both focus groups and individual interviews. Ultimately, the thematic analysis will provide a deeper understanding of informational and supportive care needs for each participant group. The aim is to use these data in conjunction with the scoping review (see chapter 2) to develop an online educational tool to help improve the quality of care and support YWHBC in the perinatal period.

The scoping review addressed empirical questions that arise for participant groups. For example, ‘Does pregnancy increase the chance of cancer recurrence?’, ‘What impact does pregnancy and breastfeeding have on hormone sensitive breast cancer?’, and ‘is it safe to cease hormone therapy in order to become pregnant?’. The thematic analysis adds participant perspectives that helps to deepen our understanding of gaps in care and resources that are still needed to support YWHBC into the perinatal period. Understanding stakeholder perspectives will help to tailor our development of an online educational resource that is designed by participants contributing to both the content and structure of the resource. Our hope is that such a resource will aid in bolstering communication between patients and providers, help support community resource development and help improve both physical and mental health outcomes for YWHBC in the perinatal period.

Methods

Participants

The study comprised three major stakeholder groups: YWHBC, healthcare providers, and community organizations working directly with YWBC, all of which are detailed below. In total, 33 participants participated in the study. See Table 1 for demographics. See Appendix A for recruitment materials.

Young Women with a History of Breast Cancer (YWHBC) (13 participants)

Average age for YWHBC participants was 39.07 years old. The majority of YWHBC participants identified as white ($n = 7$), lived in Canada ($n = 9$), had a professional degree ($n = 5$), and were married or in a domestic partnership ($n = 10$). Seven participants were diagnosed with stage 1 cancer and the majority ($n = 10$) had previously received surgery as a BC treatment. The majority of YWHBC had children at the time of the interview ($n = 11$), all of whom gave birth post-treatment and three of those reported pregnancy complications. All YWHBC identified as female ($n = 13$). Participant recruitment primarily took place online through social media outlets (e.g., Instagram, Facebook) and through a community partner, Rethink. The recruitment flyer was posted on the Rethink Instagram site, with contact information for the study coordinator (RV). In addition, members of our Sunnybrook research team personally directed three YWHBC participants to RV, though only one of them carried through with focus group interviews. Ultimately, all YWHBC participants were recruited through the Rethink website or Instagram page or by word-of-mouth from other participants. Eligibility criteria for YWHBC participants included the following: 1) women 45 years of age or younger, 2) completed primary treatment (e.g., surgery, radiation, and/or chemotherapy) for breast cancer, 3) English reading and speaking, 4) YWHBC actively trying to become pregnant (e.g., engaging in fertility treatments), currently pregnant or were pregnant, and/or had a baby in the past 5 years.

Health Care Providers (HPC) (12 participants)

The majority of healthcare providers identified as female (n=7), white (n=6), and worked in oncology (n=7). Demographic data were missing for four healthcare provider participants. All healthcare providers were directly approached through email by a member of the research team. Efforts were made to contact providers from diverse disciplinary backgrounds (e.g., medical oncology, nursing, OB/GYN, surgery) with direct experience treating women with BC who went on to conceive. Our initial plan was to conduct focus groups with providers of different expertise to generate meaningful discussion and highlight differences in experience. However, due to scheduling conflicts and minimal time on the part of providers, the majority of providers took part in a one-on-one interview. Only two focus groups were run for provider participants. No providers self-referred to the study.

Community Partners (8 participants)

All community partner participants identified as female (*n* = *8*). The majority were white (*n* = *5*), from Canada (*n* = *7*), and had a graduate degree (*n* = *4*). The majority noted that they had 'monthly' contact with YWHBC (*n* = *4*). Community partners, defined as any individual working at a community organization dedicated to supporting YWBC or YWHBC, were directly approached through email by the first author (RV). Organizations were chosen if they had direct contact with YWHBC, though not necessarily if they had programming directly related to supporting YWHBC in the perinatal period. Several community organizations responded to the invitation to participate by noting that they could not comment on the experience of YWHBC who were in the perinatal period. They cited no programming for the population, or that programming was mixed in terms of cancer site and generally focused on fertility, though topics such as ceasing tamoxifen to become pregnant may arise. Therefore, our recruitment numbers were lower with community partners than with the other populations, as they felt they could not offer insight into the topic or to the defined research questions. It should be noted that three community partners who took part in the first focus group are members of Rethink Breast

Cancer. It was only after they participated in the focus group that they expressed interest in helping recruit other participants for the study. Thus, it was decided that there was no conflict of interest in including them as both participants and study collaborators.

Table 1
YWHBC demographic and medical characteristics (n = 13)

Characteristics	Category	n
Age	Average age: 39.07 years	
Sex	Female	13
Region	Canada	9
	USA	3
	Nicaragua	1
Ethnicity	White	7
	Hispanic	2
	African Canadian	3
	African American	1
Education	High School Diploma	1
	Bachelor's Degree	4
	Professional Degree	5
	Graduate Degree	3
Relationship Status	Single	1
	Married or in domestic partnership	10
	Divorced	1
	Widowed	1
Cancer stage	1	7
	2	4
	3	2
	4	0
Cancer type	ER+	4
	PR+	1
	HER2+	1
	Triple positive	2
	BRCA 1	1
	BRCA 2	1
	Missing	3
	Surgery	
Treatment type		10

	Chemotherapy	9
	Radiation	9
	Herceptin	7
	Hormone Replacement Therapy	7
Children	Yes	11
	No/Currently Pregnant	6
Pregnancy complications	Pre-eclampsia	1
	Emergency C-section	1
	Miscarriage	1
	None	10

Table 2
Healthcare provider demographic characteristics

Characteristics	Category	n
Sex	Female	7
	Male	1
	Missing	4
Region	Canada	7
	USA	1
	Missing	4
Ethnicity	White	6
	South Asian	1
	East Asian	1
	Missing	4
Education	Bachelor's Degree	1
	Professional Degree	7
	Missing	4
Medical Field	Oncology	7
	Surgery	1
	Missing	4

Table 3
Community partner demographic characteristics

Characteristics	Category	n
Sex	Female	8
Region	Canada	7
	USA	1
Ethnicity	White	5
	Hispanic	2
	South Asian	1
	East Asian	1
Education	Bachelor's Degree	3
	Professional Program	1
	Graduate Degree	4
Organization	Rethink Breast Cancer	3
	Gilda's Club	1
	Women's College Hospital	1
	Young Adult Cancer Canada	1
	Young Survivors Coalition	1
	Doula	1
Contact with YWHBC	Daily	1
	Weekly	2
	Monthly	4
	Less than monthly	1

Procedure

The current study protocol was reviewed and approved by the Research Ethics Board of the Sunnybrook Health Sciences Centre (REB #5142), and the York University Human Participants Committee prior to beginning participant recruitment. A combination of purposive and convenience sampling strategies was employed to recruit participants for the current study. YWHBC participants were recruited through convenience sampling (Etikan et al., 2016) whereby the sample was selected based on availability and willingness to participate in the study.

YWHBC participants self-identified and were selected through an online social media platform (Instagram) posted on the Rethink Instagram page. The choice to recruit through social media allowed for a wide-reaching recruitment strategy that was not geographically limited in the hopes of recruiting a potentially more diverse participant pool. Each participant emailed the research coordinator (RV) and was screened to determine eligibility (see above). During recruitment and data collection, RV noted oddities with several participants (e.g., similar email addresses, identical narratives). Ultimately, due to suspected data falsification, three participants were excluded from the final analysis.

Healthcare provider participants were chosen through word-of-mouth purposive sampling (Etikan et al., 2016), whereby each participant was identified through the research team due to their expertise in the areas of oncology, OB/GYN, and fertility. Purposive sampling was necessary in this case to have participants with expert knowledge who could speak about their experience treating our population of interest (i.e., young women with a history of breast cancer). The justification for recruiting these experts, rather than general practitioners, for example, was that, although YWHBC may have first contact with a GP they would inevitably be referred out to expert care (Warner, E., personal communication, 2021). Research team members connected with colleagues to recruit healthcare participants through email, sharing the recruitment poster. Similar to YWHBC participants, interested and willing healthcare provider participants contacted RV to schedule the interview. Despite our intentions of speaking with a variety of experts who may have contact with this population, the majority of our participants worked in oncology (e.g., surgery, nursing).

Community partners were recruited using a mix of convenience, purposive, and snowball sampling given the limited number of community organizations with dedicated programming for

YWHBC navigating the perinatal period. Some participants were recruited given their connection to the PSO Lab and past collaborations (e.g., Rethink Breast Cancer), while other organizations were contacted via email by RV to gauge their interest in participating (e.g., Gilda's Club). Each community partner worked with an organization dedicated, at least in part, to delivering programming to YWBC. Focus groups generally consisted of team members working for the same organization. All but one community partner participant worked within a community organization operating in North America. The one community partner that did not work within an organization was a doula who had frequent contact with the medical system. She was referred to the study through another community partner participant.

Although our initial intention was to conduct focus groups for each stakeholder population, scheduling became challenging, specifically for healthcare providers. Thus, several one-on-one interviews were conducted with each stakeholder population. Focus groups have the potential for providing useful data regarding feelings, opinions, and ideas for how to improve care for the 'consumer' (i.e., the focus group participant). While traditionally used in business and industry fields, focus groups have become increasingly useful in healthcare data collection for better understanding how to improve care, which necessarily improves health outcomes (Bailo et al., 2019). Focus groups consisted of 2-7 participants, and 1-2 facilitators. Generally, approximately 4-6 focus groups are necessary to reach data saturation (Hennink et al., 2019). Further, online focus groups are likely to be more successful if they have a smaller number of participants (e.g., 4-10 participants), which allows for better facilitation and group discussion on an online platform (Kite et al., 2017).

Informed consent was obtained from all participants before data collection. Each participant received a $25 Amazon gift card for participating in the study, which were sent out through email upon completion of participation. No conflicts of interest were identified. Participants of each stakeholder group who were deemed eligible for the study were send a Qualtrics link consisting of the consent form and a demographics questionnaire (see Appendix B). Additionally, they were sent several options for scheduling the focus group.

Semi-structured Qualitative Focus Group or Interview

All participants completed a semi-structured qualitative interview or focus group session. A total of 9 one-on-one interviews, and 12 focus groups were conducted from April 2023-April 2024, ranging from 2-6 participants. All interviews and focus groups took place over Zoom. Each group or individual completed a 20–75-minute semi-structured session (see Appendix C for semi-structured protocol) depending on the size of the focus group and the participants. For example, providers took part in shorter sessions (20-30 minutes) given their time constraints, whereas YWHBC participant sessions were generally longer (45-70 minutes), the majority of which were focus group formats. As aforementioned, some participants were unable to attend focus group sessions and participated in one-on-one interviews instead. However, the interview guide remained the same. The interview protocol included open ended questions directed toward participant experience, and knowledge regarding the perinatal period after primary BC treatment. However, questions were open-ended such that we could ‘follow’ a novel idea or ask participants to expand on their own experience and expertise on the topic. Question development was guided by our research team and comprised questions that were intended to answer our research questions. Experiences, knowledge, and concerns expressed by participants also guided inquiry with subsequent interviewees. Thus, our semi-structured interview guide evolved and was adapted to reflect comments and questions from previous participants. This method of interviewing is consistent with qualitative methodology wherein data collection and analysis are conducted concurrently such that information gained in previous interviews may inform subsequent data collection (Nowell et al., 2017). YWHBC participants were asked a series of questions related to their BC history, their current experience of pregnancy and/or postpartum (and, if applicable, whether it has differed from other pregnancies), their questions and concerns about pregnancy and postpartum as it relates to BC treatment (e.g., chances of miscarriage, is breast feeding safe and/or possible). Healthcare providers and community partner participants were asked about their current knowledge of issues related to pregnancy after BC treatment, unique considerations for various patient populations, and what resources are available for women who are considering pregnancy or are in the perinatal period after BC treatment. The majority of interviews and focus groups were led by the lead author (RV) with assistance from her research supervisor (KF), and research assistant (DP).

Thematic Analysis

All focus group and interview content were audio and video recorded via Zoom Healthcare version, which is PHIPA compliant. Audio recordings were reviewed and transcribed by PSO Lab volunteers and reviewed by RV. However, in the cases of cross-talk or where unclear which participant was sharing, RV checked video recordings to ensure accurate transcription. Subsequently, all video recordings were deleted to protect participant confidentiality.

The current study employed a reflexive thematic analysis approach to transcribed data. Thematic analysis was originally presented by Braun and Clarke (2006) as a comprehensive analytic method with which to better understand and interpret qualitative data, subsequently adapted as a reflexive analytic method (Braun and Clarke, 2019) wherein the researcher plays a key role in knowledge production from a place of “theoretical knowingness and transparency”

(Braun & Clarke, 2019, pp. 594). Braun and Clarke (2006) outline a six-step process to engage in thematic analysis, which consists of reading over the dataset, coding based on meaning units, generating initial themes, developing and reviewing themes, refining, defining, and naming themes, and writing up (2006). While other approaches are often used in health research (e.g., grounded theory, interpretive description), thematic analysis offers a rich and digestible presentation of data, which may not only help to answer a particular set of research questions but also lay the foundation for resource development and applied research. Further, thematic analysis is well established in health research given the effective processing of large datasets into manageable summaries of the content (Saunders et al., 2023). Specifically, research that extends outside of academia and into practice and policy arenas, with accessible reach to broader communities (Braun and Clarke, 2014). This qualitative approach allows researchers to identify themes and patterns throughout the data, helping to highlight and synthesize important areas of content.

Thematic analysis may use either inductive, or deductive approach to coding. The inductive approach allows for ‘bottom up’ analysis, whereby coding is entirely emergent with no predetermined framework of analysis. Doing so allows researchers to code through an exploratory lens, which was important for the current study to capture participant experience. Deductive coding uses a top-down approach, drawing upon pre-existing theoretical assumptions and categories, which are then applied to the dataset, often to confirm or refute existing theories (Braun & Clarke, 2006). Both were used for the current study, given that likely themes were discussed a priori with the research teams (e.g., breastfeeding) and were used to guide the development of the semi-structured interview guides. For example, the deductive approach was based on a team guided experience (e.g., all members of the research team other than R.V. and

K.F. are medical doctors who work directly with YWBC who are attempting to become pregnant). In addition, during our qualitative data collection, the lead author was simultaneously conducting a scoping review of the literature, which revealed main themes such as recurrence, pregnancy outcomes, and breastfeeding. Thus, we included questions based on such topics given their relevance in the empirical literature and these questions drove, in part, identified themes. Despite previous empirical knowledge regarding main issues identified for this population, we remained open to emergent themes that added context to the unique experience of ‘kids after breast cancer.’ The research team anticipated that provider interviews and focus groups would be primarily focused on practical concerns and medical barriers and advancements, while we assumed that YWHBC themes would centre more around the distress of the experience, fear of cancer recurrence, and worry about child’s health. Our predictions regarding the emergent themes were influenced by the current empirical landscape. While our goal was ultimately pragmatic (e.g., development of education tool), the current study also employed an interpretive phenomenological epistemological framework (per Willig’s (2012), definition of such), integrating participants’ personal experiences navigating the perinatal period after BC (whether having lived it themselves or being involved in a circle of care). This was true of all stakeholder groups, not just the YWHBC population. Our dataset was rich with metaphor and meaning, illustrating not just the practical medical aspects that a history of BC introduces to the perinatal period, but also the nuance and complexity of this experience, from the YWHBC, healthcare, and community perspective. We sought to understand participant perspectives regarding the perinatal period after BC with the ultimate goal of designing an online educational tool guided by participant experience to foster empowerment, communication, and improve continuity of care.

Once all focus groups and interviews had been transcribed, RV began to review transcripts. Each transcript was thoroughly reviewed and read over several times before RV began sequentially coding each transcript for salient themes regarding the safety of pregnancy after primary treatment, birth outcomes, reproductive concerns, and breastfeeding after cancer treatment. Deductively derived, higher-order themes captured stakeholders' informational needs regarding pregnancy, birth outcomes, and breastfeeding. However, throughout the coding process, other themes were derived inductively, meaning they were not previously identified as themes that may be relevant for the population. Themes such as time pressures, fertility guilt, and inadequate supports throughout the perinatal period were also identified and coded. Throughout the process, RV and KF met to discuss themes. Agreed upon themes were named and applied to each transcript and then refined to generate clear definitions. Thematic analysis utilizes the constant-comparison method (Glaser & Strauss, 1965) throughout analysis, wherein the researchers constantly move between the original text and identified themes producing a form of internal validation (Rennie, 1998). Throughout the analytic process, we also used memoing and reflexive disclosure to ensure transparency of the development of themes and provide an audit trail for members of the research team.

Reflexivity Statement

As a researcher, I take a critical-realist stance to knowledge exploration and creation. The critical-realist epistemology takes each participant's account at face value, assuming it is real and reflective of their individual experience. However, the data do not represent an objective reality but rather, are interpreted through the participant's social-historical lens, which may differ for each participant (Willig, 2012). Thus, the critical-realist lens recognizes that phenomena have 'layers' of meaning, which contribute to participants' and researchers' conscious interpretation of the participant's experience, while also being shaped by underlying, enduring structures (e.g., culture) that subconsciously contribute to meaning making (Sims-Schouten et al., 2007). My goal as a critical-realist is to conduct research that illuminates the experiences of individuals who have been historically disenfranchised by giving them a voice and better understanding what is needed to help empower them in situations in which they have felt powerless. For example, in the context of this research, I acknowledge that YWHBC participants have had to rely on institutions for medical care that often 'center' the healthcare provider as the holder of knowledge, rather than the person seeking care. Such experiences were discussed in my previous research (Vanstone et al., 2021), wherein young women with a history of cancer felt lost within, and often let down by, the healthcare system. Thus, it was important for me when undertaking the current research to continue to help center participant voices and aim to work more collaboratively with the systems (e.g., hospitals, community organizations) that they rely on for support. By including healthcare providers and community partners in the conversation, I hope to further ensure future providers have a 'stake' in the outcome, encouraging perspective taking and collaborative decision making.

It is further important to acknowledge that I have had personal, professional experience within the hospital system. Working on an inpatient service in Halifax while writing this dissertation gave me 'insider knowledge' of the 'cracks' in the system that disadvantage many people who must rely on the hospital and community programming for medical and emotional support – many of whom have been navigating the hospital system for many years. Despite the incredible dedication of the doctors, nurses, social workers, and program developers that work within these systems, they are rarely set up to empower. It is often the responsibility of individuals (patient, healthcare provider, community partner) to advocate for themselves and others.

Finally, and more practically, the interviewers, RV and KF had previous knowledge on the topic and discussed, in-depth, issues that arise regarding patient care prior to conducting the focus groups and interviews. Thus, it is likely that our prior assumptions may have, in part, shaped how we approached the interviews and interpreted the transcribed data. Additionally, the current study had the ultimate goal of resource development, which may have impacted the analysis such that the focus tended more toward tangible and pragmatic outcomes. However, while we were ultimately focused on uncovering needs that would lend themselves to resource building, these findings are bound to the complexity of an institutional structure which necessarily impacts YWHBC, provider, and community partner experiences of kids after BC.

Results

Each higher-order category is comprised of codes reflective of the full sample, which speaks to the congruence between the subgroups that were interviewed and how aligned participants were with regards to the experience of navigating the perinatal period after BC. The following thematic analysis presents a linear ‘storyline’ which may help to make sense of this unique experience for patients, healthcare providers, and community partners alike. However, it is necessary to highlight that this experience is likely not perceived as linearly as presented in our analysis and patients do not simply ‘move’ seamlessly from one theme to the next. More likely they ebb and flow between them. Within each theme we have identified sub-themes. Each sub-theme contains superscript, denoting which subgroup contributed to the development of each theme and sub-theme[6].

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[6] Subgroups of participants are indicated beside sub-themes as follows: P=YWHBC participant, H=healthcare provider participant, and C=community partner participant.

On the Clock

The theme, ‘On the Clock’ represents the inherent time constraint that patients experience as they plan for and navigate the perinatal period. This delineates the beginning of the perinatal journey for patients, encompassing the time before entering the perinatal period, and possibly even before beginning BC treatment. Decisions at this point may be crucial to their ability to conceive after BC treatment.

Decide the Future Now$^{\mathrm{P,\,H,\,C}}$

This sub-theme represents the pressurized decisions patients must make often immediately after their BC diagnosis. If following standard protocol, providers present options for fertility preservation and BC treatments that have direct implications for patients’ ability to conceive post-treatment. Many participants, YWHBCs and healthcare providers alike, noted the overwhelm that accompanies such decisions, especially as patients must simultaneously process the diagnosis and treatment of BC. YWHBC participants discussed that they were unable to remember fertility conversations, or conversations about their plans for the future as the rush to preserve eggs or embryos is interwoven with treatment decisions. As one healthcare provider noted, “They have to decide how they see their survivorship. They have to process how they're going to see you know what, five years looks like, what, 10 years looks like” (H02). In addition, each of these decisions are intrinsically linked. Given that young women with BC are often diagnosed at a later stage of disease (Xu et al., 2024), there is a necessary urgency to begin treatment as soon as possible, which puts added pressure on patients to decide whether to pursue fertility preservation when they may not have even begun to consider having children. One YWHBC participant highlighted this experience, sharing,

> Literally, I think when I got diagnosed, I had my first appointment um virtually on like a Tuesday and then on Wednesday I had to start IVF. So just that rush and also like meeting with surgeons and stuff like that. (P13)

Deciding the future 'now' also continues after treatment as patients consider options for fertility, pregnancy, and breastfeeding. For example, considerations about pursuing IVF for patients who have had hormone sensitive BC introduces additional uncertainty and hesitation. As one participant so aptly put it, "While it is, you know, an emotional, personal decision, no decision that I get to make at this point isn't informed by my cancer diagnosis" (P42).

Informational Lacuna**P, H, C**

This sub-theme speaks to the gaps in information that stakeholders identified as necessary to be able to make informed decisions, such as information regarding the impact of cancer treatment on family planning and the postpartum period. All participant subgroups noted that patients get 'bits and pieces' of information that help with long-term planning (e.g., fertility preservation) but patients often feel rushed, confused, and underprepared for conception after primary BC treatment while health care providers feel underinformed. As one oncologist stated, "I don't know enough about this. [laughs] Now that you're interviewing.... I have a lot of gaps in my knowledge. So, what would I tell a patient if they came to me tomorrow and … have these sort of questions? I'd have to call you guys" (H17). Such gaps in information leave patients unaware of the long-term impact and consequences of their treatment and fertility decisions, thus potentially altering their survivorship goals (e.g., postponing pregnancy for secondary treatments such as endocrine therapy). Furthermore, healthcare providers may be solely focused on disease management, rather than post-treatment quality of life - therefore missing important pieces of information that help with long-term planning for patients. "I work at a like an academic centre… in the cancer centre. So, like everybody's focus and like tunnel vision is like cancer" (H15).

Similarly, all YWHBC participants noted the lack of information as a distressing piece of the process,

> I remember being frustrated because there just wasn't information… my doctor was like, yeah, we just don't know. Yeah, that's… we're not the first women in the world getting pregnant after breast cancer. I'm sure. So, like, why is this? You know, why is there not enough information or what's missing…? (P26)

***Hurry Up and Wait…Alone*$^{\mathbf{P, H, C}}$**

This sub-theme speaks to the timeline considerations unique to YWHBC. Most stakeholder groups recognized the difficult position women are in once they finish primary BC treatment. Patients are eager to turn the page on cancer and focus on accomplishing survivorship goals but are generally told they must wait before trying to conceive. Each participant group identified the concern with time pressures (e.g., getting older) and that patients often feel rushed to begin trying to conceive, though doing so may compromise treatment gains. As one community partner stated, "…I think age has a lot to do with it, like a lot of people in the community are like mid 30s and are like, ok, if I have to wait five years, then I'm 40 and then the chances of my fertility drop..." (C08). In addition, they may be required to take secondary treatments (e.g., endocrine therapy) that are contraindicated with pregnancy, thus further disrupting family building plans.

To compound the pressure of having to decide how to balance treatment benefits and quality of life, women often find themselves without routine, or specialist care when they enter the perinatal period. YWHBC participants noted feeling unsupported and unsure of how to manage changes in the body, such as changes in the breast that are, understandably, distressing. All participants talked about how distress is compounded during this time when patients feel that they do not have access to appropriate care given their complex medical history. Of particular concern is that patients are not referred to an OB/GYN until their second trimester, which means they are left to worry about whether physical changes are natural or concerning. As one healthcare provider stated of her private fertility clinic,

> Our fertility clinics will get women pregnant and then they don't follow them – and then they have no primary care providers. And so they're left in that period between six to twelve weeks before an OB will see them. And it's obviously a high stress period for them, and they're just kind of abandoned. (H09)

One YWHBC spoke directly to this experience, noting,

> And I haven't met my OB yet. And like my IVF doctor is not the right person to ask some of these questions to, but something I'm like wondering or have been wondering about is like, I've had a double mastectomy, but pain in the chest area or sensitivity, which I assume is like residual breast tissue. Nothing feels…hard or weird or concerning… it would be nice to have some reassurance that that is normal. I'm also in some Facebook groups, I think one is called maybe babies after breast cancer, but I've seen people post about like having kind of like lumps in the armpit area after giving birth, which is like milk ducts and I'm like, is someone going to talk to me about that at some point? Like, I don't know things like that, but like… most people is [this] not part of, I guess, typical education about what to expect after you give birth? Because I haven't got my OB yet, we haven't talked about like feeding. But that's like something I am concerned about, like

> being in the hospital and have people come in and ask about that, which is not possible. (P47)

The unique experience of having to wait to become pregnant and then to be referred to an OB/GYN while also navigating the first stages of pregnancy was described by some participants as being "in limbo." This description very aptly illustrates the isolation felt by YWHBC as they shift focus from cancer to pregnancy. This may be especially true for those women who are more than 2 years out from primary treatment and relying on their family physicians, rather than specialist providers, for medical support.

Setting Realistic Expectations$^{\mathbf{P,\ H,\ C}}$

All subgroups endorsed the idea of setting realistic expectations throughout the perinatal period. However, expectations are continually being adjusted, and patients and providers must consider what is realistic going into each new phase (e.g., treatment, post-treatment, conception, and perinatal period). Each new set of expectations is dependent on decisions and outcomes of the phase before. For example, if a patient does not receive GnRH agents during chemotherapy (drugs that help to suppress ovulation and protect ovarian reserve during treatment), they may only be able to use eggs or embryos preserved before treatment, thus eliminating the chance of becoming pregnant naturally. All groups recognized the importance of setting such expectations to reduce distress at each stage. As one participant stated how she managed disappointment throughout this period,

> It's just kind of like one of those things where you just have to kind of accept and learn from it… hopefully… And I don't know, maybe that's a selfish way of looking at it, but I feel like, unfortunately, just like with all the side effects of all the medicines that you're on as a cancer patient, unfortunately, that's one of them. (P37)

Needs Change Over Time$^{P, C}$

This sub-theme represents the shifting needs of patients as they navigate the trajectory of treatment into the perinatal period. Over the course of this trajectory, patients' needs evolve and may even shift back and forth in a non-linear fashion, whereby they require different support services, and different provider expertise based on their current point in this timeline. Both community organizations and healthcare providers endorsed this category and recognized the need for shifting supports and information throughout the treatment and perinatal periods.

Cancer History Intensifies Perinatal Distress

While there is ample evidence showing that young women are particularly vulnerable to increased psychosocial distress after BC treatment (Ahmad et al., 2015), we found that the participants identified becoming pregnant after BC as adding to their distress. Sometimes in line with existing literature (e.g., fear of cancer recurrence), and sometimes in distinctive ways (e.g., uncertainty about breastfeeding). This category encompasses both, highlighting the more general worries that accompany a cancer history as well as specific worries that arise for YWHBC who are in the perinatal period.

A Unique Type of Distress$^{P, H, C}$

The beginning of the perinatal period marks a uniquely distressing time for patients during which they experience heightened anxiety regarding body changes, worry about the impact of pregnancy hormones on cancer recurrence, and uncertainty about the health of their fetus. While women in the perinatal period are considered more psychologically vulnerable to distress (Davis & Narayan, 2020), a BC history adds a unique layer to their worry. Participants identified that distress may also intensify given women may not have timely access to healthcare and resources to help ease the uncertainty. This 'chapter' in the cancer-perinatal journey interacts with the pressure of time and feeling ‘in limbo’ for some of these women, which heightens distress.

***Fertility Guilt*$^{\mathbf{P, H, C}}$**

The BC community is highly supportive and generally well resourced, and many YWHBC and community partner participants endorsed a strong sense of support from the BC community as women navigate into the survivorship period. However, YWHBC participants identified that becoming pregnant may introduce a sense of guilt, given that they are aware that friends and other community members are struggling with infertility, or metastatic disease. YWHBC participants identified that this leads them to feel as if they need to pull away from community supports so as not to ‘rub’ their pregnancy in other’s faces. However, doing so leaves them isolated and unsupported during the perinatal period. Many women noted that they felt there was no dedicated space for them to talk about their experiences and challenges during the perinatal period, which intensified worry. As one participant said,

> I feel like about half of us have had no problems getting pregnant and then like another bunch of, the other half of, like the girls that I've been like close with and close in age with who went through treatment around the same time I did are having trouble. So absolutely, I could understand feeling guilty. And yes, I do have that sense of guilt. (P37)

Participants seemed to also express a sense of protectiveness for others in the community, and an understanding of what they must be going through by not being able to become pregnant. Another participant shared,

> I guess like the only thing that I found was within my group of breast cancer friends. One of my friends is metastatic, another has removed her ovaries before she had children. So, we're really kind of cognizant about talking about children too much because it's quite

> painful for them because they were… that opportunity was taken away. So, I definitely think there is a need for some separate space at times, just to protect peoples'…sort of loss around that that can come with your breast cancer diagnosis. (P12)

This phenomenon of pulling away from the cancer community when YWHBC become pregnant was also identified by community partners. As one stated,

> Sometimes folks that are struggling with things throughout their pregnancy that's still connected to their cancer experience and are hesitant to bring it forward because they have this feeling of like, "but I should be thankful I'm in this position," and so I tend to have more of those folks reach out to me one-on-one for support because they feel like they shouldn't be raising it in the larger community. (C01)

Cancer Reminders $^{\mathbf{P,\ C}}$

At various points throughout the perinatal period, participants discussed reminders of cancer (e.g., high-risk pregnancies due to treatment, fear of giving birth due to impact of treatment) and fear related to their physical health. While increased worry about scans and routine ultrasounds is common with cancer survivors (Simonelli et al., 2017; Koch et al., 2013) women in the perinatal period are reliant on hospital care and institutions to help maintain a healthy pregnancy, which may cause increased distress because of the association between hospital-based care and cancer treatment. Both YWHBC and community partners recognize the precarious position that this puts women in, especially if or when providers are not trained to use trauma informed care in the context of cancer history.

Participants also recognized that, during pregnancy, this population is likely to be labelled as 'high-risk' because of the lasting physiological impact of cancer treatments (e.g., increased strain on the heart), possible more advanced age, and monitoring for signs of recurrence. As one woman stated of her experience of being labelled ‘high risk’, “It was not super great emotionally because I go into this being like I'm super high risk. It's all going to be like super scary and going to have to be super concerned the whole time” (P42). One woman spoke of her anticipation of giving birth, sharing,

> I think during the pregnancy, one of the things that I was actually quite fearful of was the birth itself. Particularly having that be very medically managed. Because so much of my life up until that point had been very medically managed. And so being able to go into it and have it be more of that sort of experience for me…it was really like I didn't want to have to be cut open because I just had a lot of trauma around lying on tables and being cut open, and particularly while being awake. (P39)

In addition, several women noted that they worried about coping with new stressors after giving birth (such as the health of their child) and questioning whether they were psychologically strong enough to manage the role of motherhood after having survived BC. For some women, worrying about their child intensified memories of their cancer experience, making their concerns about recurrence more salient.

Breastfeeding Challenges$^{\mathbf{P,\ H,\ C}}$

Various challenges to breastfeeding are unique to this population. While very little research has been done on the topic, each stakeholder group identified breastfeeding as a main concern and challenge that many YWHBC will encounter during the postpartum period. While some women noted acceptance of not being able to breastfeed (e.g., after a double mastectomy), others shared that they struggled with decisions around breastfeeding versus formula feeding, and feelings of shame at not being able to breastfeed. One participant spoke about her emotional reaction to being unable to breastfeed after giving birth, despite attempting to breastfeed. She shared that she felt as if her child really needed breastmilk, and that she was “ashamed that I wasn't able to [breastfeed] because of what happened to me” (P26).

In addition, questions and concerns around breastfeeding often go unanswered. The majority of stakeholders identified that breastfeeding resources are scarce. Questions regarding the safety of feeding from a treated breast, the implications of producing colostrum or milk unexpectedly, and the chances of mastitis due to scar tissue build up were all unanswered for patients, leaving them unprepared to deal with breastfeeding challenges as they arise postpartum. Compounding these concerns is the primary goal of nourishing their child. As one participant stated, “…it wasn't easy to cope cause at that point, I felt like how would this child survive without the breast milk? I had to look for another alternative by getting something else” (P31).

Finally, breastfeeding education was also identified as an important consideration before beginning BC treatment, given that the majority of treatment decisions are likely to impact the ability to breastfeed in the future (e.g., surgery, radiation). All stakeholders recognized the importance of healthcare provider knowledge or referral to lactation specialists who can provide guidance and set expectations around breastfeeding.

We’re All in the Dark

Each stakeholder group acknowledged their own limited knowledge in the area of perinatal health after BC. While each recognized that there are some supports to guide patients throughout the perinatal period (e.g., well-established guidelines, access to lactation specialists) such resources are in the beginning stages of development. Given that healthcare providers are generally the first-line knowledge holders, they must always be playing ‘catch up’ with up-to-date information provided through conferences and research papers. Thus, patients may receive inconsistent information between providers (e.g., oncologist to gynecologist), which again impacts their ability to make informed decisions about their care. In addition, community organizations generally rely on their community members for input on gaps in resources such that program development is initiated in response to community needs. Given the relatively new focus on pregnancy after BC, there are very few community resources dedicated to support for this population. In fact, none of the participants were able to identify a program that specifically supported having children after breast cancer.

Doing the Best With What We Have^{H}

The dearth of information on the topic of KidsABC makes it difficult for healthcare providers to counsel their patients on how best to navigate the perinatal period. For example, BRCA 1 and 2 carriers are at an increased risk of recurrence (Yoon et al., 2019), and very little research has been dedicated to understanding the impact of pregnancy on recurrence outcomes. Therefore, healthcare providers are less able to offer empirically grounded advice regarding pregnancy. The lack of empirical data available for YWHBC introduces uncertainty for both patients and providers. While research in the field of perinatal health after BC is growing, healthcare providers rely on guidelines to counsel patients, and some point out that certain guidelines may never exist (e.g., safety of using assisted reproductive technologies (ART) to become pregnant). The lack of guidelines is due to the number of individual differences in the BC population, and the lack of RCTs that are able to determine causal outcomes. One provider noted that up-to-date information may come directly from the healthcare community (e.g., at conferences) but such presentations are generally reserved for ‘groundbreaking’ topics, rather than niche research areas. As she said, “it's very much the bias of the presenter that will dictate the knowledge of the community oncologists” (H04). Another pointed out the gap between “knowledge creation and knowledge dissemination” (H03), which means providers are often relying on generalized international guidelines that may not adequately address patient specific needs. Thus, healthcare provider participants recognized that they must do the best with the information available to them, striving to ‘strike the balance’ between available evidence and patient goals to deliver the best treatment option available.

Need for Clinical Care Guidelines$^{\mathbf{P,\ H,\ C}}$

The lack of available data and guidelines for how to proceed with planning for pregnancy makes treatment decisions and program development difficult to achieve with certainty. Each stakeholder group shared their frustration in dealing with informational uncertainty while recognizing that they may never have concrete answers. Healthcare provider participants noted that it may be unreasonable to expect widely applicable guidelines, given the individual health considerations of each patient (e.g., cancer sub-type, age, comorbid health considerations). However, they identified the importance of knowledge dissemination to educate physicians who do not provide speciality care, but who may be the main point of contact for many YWHBC. For example, family physicians working in rural areas may have no knowledge regarding the considerations of pregnancy after BC, which leaves patients responsible for engaging in their own research, or without any pertinent guidance on how to navigate the perinatal period. Both healthcare providers and community partners highlighted the need for specific guidelines on how best to care for this unique population and the importance of widely disseminating these guidelines.

Finer and Finer Distinctions$^{\mathbf{H,\ C}}$

Medical advancements have allowed for more tailored treatment for YWBC, as well as innovative oncofertility options regarding pregnancy after BC (e.g., GnRH agonists). However, while research focus in this area is promising, healthcare provider and community partner participants point out the disadvantage of newly developed treatment options outpacing empirical testing during the perinatal period. For example, healthcare providers expressed concern with advancements in BC treatment that may have a better overall prognosis but different impacts on fertility and pregnancy for BRCA carriers or HR+ cancers than well-established treatments.

Advancements introduce increasingly complex considerations for YWHBC, including the impact of cancer type and treatment, genetic mutations, safety of ART, ability to breastfeed, and screening procedures. While more information is the ultimate goal, it can introduce increased uncertainty of outcomes, which is difficult for patients to manage. As one community partner stated, "…it's this hard thing of, you know, slowly getting more information about this…but then more questions come up and it doesn't work for everyone. And then it's just it's further isolating, and they have even more questions" (C03).

Bridging Communication Divides

This theme represents the silos that emerge when patients transfer from one area of specialized medical care to another. In this case, all stakeholder groups noted that the communication between oncology, fertility, and perinatal health can be poor due to the specialization of care. All stakeholders mentioned that an increase in communication between providers is more common in centralized hospitals but becomes less common in rural communities or when women seek care at private clinics (e.g., fertility clinics). In such cases, the transfer of health data and collaboration between providers may negatively impact clarity of treatment and, thus patients' treatment decisions.

Connecting with Other Supports^{H,C}

Both healthcare providers and community partners noted the importance of having contact and open communication with others in their field. For example, healthcare providers will attend continuing education seminars, conferences, and case rounds to access knowledge and data around perinatal health after BC. Providers specifically stated that cutting edge data may only be accessible through such avenues and thus find it imperative to remain steeped in the research community to stay up to date on new developments.

Such access helps to begin the chain of knowledge dissemination. However, access to emerging scientific data may be limited for providers who work in rural settings, as well as community partners. Those such as doulas and midwives who have later stage contact with patients may benefit from early and open communication with healthcare providers, especially when they have patients that opt for a less medicalized pregnancy, if possible. Communication becomes increasingly important at this point due to the high-risk pregnancy status, risk of recurrence, and general monitoring that is needed for YWHBC. Even between healthcare providers, gaps in communication can make it difficult to provide continuity of care. One oncologist noted her attempts to integrate care in their clinic, stating,

> We submitted a grant, just trying to get this multidisciplinary program that would involve fertility on site so that we can actually talk *laughs* like physically talk as opposed to just, you know, faxing things back and forth to each other, which is how it works now. (H09)

Requiring A Web of Expertise^{P,C}

Both healthcare providers and community partners acknowledged the need to rely on external sources of knowledge and support to meet patient needs. Healthcare providers recognized that they can counsel patients with knowledge in their own 'wheelhouse' but rely on other experts (e.g., OB/GYN) in the field to consult on and convey medical considerations and evidence in relation to pregnancy after BC. Both healthcare provider and community partner participants cited interdisciplinary communication as integral to continuity of care. This is especially important for providers who do not work in high-volume urban centres where there is more likely to be a multidisciplinary approach to care between healthcare teams. For example, internal program referral and expert consultation are often relied on for support, so those who work in private clinics or remote areas do not have easy access to multidisciplinary consultation. Healthcare providers also noted the importance of training other team members in order to maintain continuity of care. Community participants stated that it helps to be in communication with others in the field in order to effectively deliver up-to-date content and aid in program development.

Finding the Through Line$^{\mathrm{P,\,H,\,C}}$

Both healthcare providers and community stakeholders requested good referral sources for patients, which is integral for continuity of care. Similar to above, they noted the importance of having consistent care but noted that there are various gaps throughout the perinatal period. All stakeholder groups acknowledged shortcomings of the medical system when it comes to referrals to specialty providers within their communities. Healthcare providers and community partners noted that given there is little amalgamation of evidence, they rely on referrals to experts in the field (e.g., OB/GYN specializing in high-risk pregnancies), patient advocacy groups, and psychological support providers. Doing so helps to address medical and emotional needs, above and beyond what individual providers or community programs offer. Additionally, there is often a lack of communication between healthcare providers and community partners. Both groups recognized that healthcare providers may only be aware of, or refer to one or two community organizations, and in turn, community organizations have little contact with healthcare providers throughout the perinatal period. All stakeholder groups identified the burden that this lack of communication can put on patients (e.g., independent research, self-advocacy), and that improved care will include bolstering communication between all parties.

Trusted Information Guides Decision Making

Each stakeholder group underlined the importance of having access to empirical evidence from a trusted source that they deemed necessary to help guide counselling, patient support, and decision making (e.g., treatment). However, each group identified that merely 'Googling' to find information may be overwhelming for patients, as doing so does not always produce trusted websites or information. Thus, having a reliable information source was flagged as being a prerequisite to improved care.

Trusted Source[P, H, C]

Each stakeholder group identified the need for clear, concise information from a trusted source to enable informed decision making and improved communication. Community stakeholders and healthcare providers noted that they would like to be able to direct patients to a vetted site or brochure that they trust to provide up-to-date and empirically grounded information to educate and guide decision making after BC treatment. All groups identified community organizations as an integral resource that helps to equip patients with reliable information to educate themselves and guide advocacy, conversations, and questions to their healthcare team. Several healthcare providers noted that they often refer patients to well-established community organizations for added support. These organizations therefore play an integral role for YWHBC as patients rely on them as a trusted source of information. Patients also rely on their healthcare providers to address medical concerns or as a source for additional resources.

Information On Repeat[P, C]

YWHBCs and community partners noted the importance of information being conveyed multiple times throughout the cancer and perinatal trajectory, including having a rationale for treatment decisions (e.g., Does waiting 2 years to become pregnant make sense, and why?). Specifically, both groups noted that patients often receive information on more than one occasion, but in states of high distress (e.g., returning to hospital for ultrasound, mammogram) wherein they have trouble recalling important details of the conversation. Having readily accessible information when the timing is right for each individual YWBC, (e.g., breakdown of terms and jargon) helps to make more rational and supported decisions. YWHBC in particular noted that they are often required to make 'high stakes' decisions about their health and treatment with lifelong implications (e.g., fertility preservation, breast conserving surgery) – hastily and early on in the process. Thus, they stressed the importance of being able to have access to such information as if 'on repeat' so they could make updated decisions as they navigated both cancer treatment and the perinatal period. One community partner participant noted that being able to revisit information may also relieve stress, stating, "it also forces them to not think about this issue if they're not ready to think about the information like, they can process everything else and then they can go and look at it later" (H02).

Generalized Perinatal Information Just Doesn't Cut It

Stakeholders identified that available information is often generalized from other populations (e.g., YWBC, perinatal population) but lacks the nuance necessary to address specific patient needs; not only for the YWHBC community as a whole, but for each individual.

For example, YWHBC and healthcare providers noted that even the most common guidance given is to wait two years before becoming pregnant after BC treatment. However, YWHBC often questioned this information, wondering how and why the guideline applied to them – especially those with BRCA mutations or HR+ disease.

Tailored Care$^{\mathbf{P,\,H,\,C}}$

Each stakeholder group noted that tailoring care to each patient is integral for quality of care and has a significant impact on patient experience. Many YWHBC noted that they felt more distressed when healthcare providers gave them generic answers to their questions rather than taking the time to explain the impact of their individual treatment or cancer type on pregnancy. One YWHBC participant spoke about her healthcare provider reviewing medical considerations with her (age, primary and secondary treatments), and then referring her to a fertility doctor who specialized in BC. She noted that, "it was really helpful to get those referrals…so I could get some information from fertility doctors who had experience working with women who had gone through breast cancer treatment" (P26). Tailoring care also becomes important for women's confidence entering into the perinatal period. Another YWHBC shared that her healthcare provider reviewed her odds of recurrence during pregnancy. She noted that, because she has a BRCA 2 mutation, it was important for her to find specific information about the impact of the BRCA variant and her cancer type on pregnancy. She said, "they did find me a study…and they can't tell you for sure, because nothing's a guarantee, but I was confident in the information that they gave me" (P16).

Stakeholder groups all recognized that providing tailored information helps women feel more confident in their decision to become pregnant and reduces distress throughout the perinatal period. This may be especially true if women are labelled high-risk during their pregnancies. Knowing where the risk stems from for each individual patient is important. One YWHBC participant noted that her OB labelled her high-risk due to her relatively older age but said that she did not speak specifically to the impact of her cancer treatment or type and “just kind of grouped them together and…didn’t tell me anything specific” (P37). Healthcare providers shared that YWHBC are often considered a high-risk group during pregnancy due to the possibility of recurrence (at any time), for women who may have cardiomyopathy during chemotherapy, and other pre-existing comorbidities (e.g., compromised liver function due to cancer drugs). Therefore, the term ‘high-risk’ may not apply in the same way to this population as other high-risk pregnancy individuals (e.g., due to age). This is especially important for communication between stakeholders as details about each individual (e.g., whether they have had fertility treatments, whether they plan to have children in the future) may determine treatment course, follow-up, and contraindicated medications. As one community partner said of what she envisioned as ideal care, “…somebody that would come in like a nurse navigator or somebody that would come in and kind of help you walk through the journey of pregnancy and cancer. That's something that really, it doesn't happen as much” (C10).

Finally, YWHBC participants highlighted the importance of finding a good fit for their care. Women may access online survivorship support groups or mental health supports but can still feel isolated and alienated if they do not feel it is a good fit (e.g., attending BC survivor groups for all ages with no discussion of having children after BC). Having access to groups that address the specific needs and concerns for this population, as well as being in contact with others who have had or are going through similar experiences may help to ease feelings of isolation during the perinatal period. One YWHBC participant shared that she was told she was the first pregnant woman with a history of BC that had been diagnosed in her country. She spoke about finding the Rethink Network, noting, “It was really reassuring for me that I wasn't… the only one, that there were other women who were going through this…and they could relate to what I was going through” (P28). She went on to say that it made her feel less isolated and more validated in her experience of pregnancy after BC.

No Substitute For One-On-One Pregnancy Consultation$^{\mathbf{H, C}}$

Taking the time with each patient to explain pregnancy-related risks and mitigating strategies (where these exist) is important for deeper understanding of the trajectory of both their disease and pregnancy and to help them make informed decisions regarding their care. All stakeholders recognized the fact that there is no substitute for one-to-one, individualized care, as it allows patients to collaborate with their healthcare providers, ask detailed questions about their pregnancy plans, and develop a workable path to, through and beyond pregnancy. While there are online resources that healthcare providers may direct patients to, the lack of interaction introduces more questions and uncertainty, placing the burden on patients to search for more information or try to access supports that can help answer their questions. One healthcare provider spoke about the importance of individualized care not only to help inform but also empower patients. She noted that, “I think for them the one-on-one kind of consultations with experts in the field who have an interest in this area would be so helpful to empower them to make the right decision for themselves” (H04). Healthcare provider participants also recognize the time pressures that they are under and are aware that it is not always realistic to dedicate the time they would like to each of their patients. Therefore, providers are often tasked with balancing one-to-one care and knowledge translation such that their patients feel supported throughout the perinatal period while navigating the challenges that arise during the perinatal period (e.g., assessing breast lumps).

Taking Back Control

After going through cancer treatment, patients cope and process in different ways. Stakeholders identified coping mechanisms that help patients to process their cancer journey, including focusing on their own health, finding sources of support to cope, and beginning the perinatal chapter, which participants recognized as another major life event. Finding ways to take back control after the whirlwind of cancer treatment was identified as an important component of the bridge between recovery and pregnancy.

Strength Building for Family Building$^{\mathrm{P,\,H,\,C}}$

After the initial treatment phase and recovery, patients may turn their attention to focus on rebuilding their lives after cancer and working toward their family building goals. A key component of this phase for many patients is finding ways to strengthen their bodies in order to prepare for pregnancy. Both healthcare providers and community partners also noted the tendency for patients to want to focus on their physical health. YWHBC identified wanting more information about which supplements may be most helpful for helping rebuild their immune systems, exercise programs, and healthy diets to help support future pregnancies. Given that many YWHBC participants were counselled to wait for a 2-year period between the end of treatment and attempting to become pregnant, many noted that it was helpful to have a goal, or physical markers of health during that time (e.g., healthy enough for the return of menses). One community partner, a doula who works with YWHBC noted that many of her patients want to focus on overall wellness. She stated,

> I do find also that there is a focus or there tends to be on just like overall holistic wellness for people going through pregnancy that have been through cancer treatment and like mind body wellness… even outside of the pregnancy stage and phase, just more

> awareness of, like wanting to do things that are good and supportive for their overall health and well-being… even just in terms of like nutrition and other ways of like supporting their overall well-being and ways of helping them to like regulate their nervous systems. Going through like helping through any like anxiety that might come up along the way as well. (C15)

Many community programs now offer holistic approaches to health such as yoga, nutrition, and mental health supports that may be integral in helping patients manage distress after treatment. As one YWHBC participant said, "…I should do more. I should exercise, do more exercise. Eat, sleep, rest and get myself together" (P35).

***Educating Ourselves*^{P, H}**

YWHBC and providers identified that many women, especially younger generations of women are arriving to appointments having already done research about their specific cancer type and what is needed to support a healthy pregnancy after cancer treatment. YWHBC participants identified that much of their motivation to find information stems from not being given information from their healthcare providers (e.g., family doctors), and finding power in knowledge. They expressed that they felt they had to take it upon themselves to do their own research in preparation for treatment, fertility preservation, and planning for pregnancy. As such, healthcare providers recognized that patients often teach them about aspects of the KidsABC experience that they may not have been aware of prior to seeing the patient. As one healthcare provider said,

> I find the younger generations are very empowered by knowledge. They come in and they're like, I want this treatment plan, sometimes to a default [laughs]. But I feel like the prompt... It's good because the prompt is coming from them to say that I want to have

> this, and I want to make sure that it's there. So, I think that prompt is helpful and that I'm getting a much more knowledgeable patient population. (H02)

Another provider shared,

> I sometimes find the patients more educated than I am, to be honest. In this particular scenario, they've done a lot of research, a lot of reading and come to me with questions that …I'm not always able to answer. (H07)

Finding My Perinatal Point Person^H, C^

Both healthcare providers and community partners indicated the empowerment that can come from patient support such as having someone to rely on for information, support, and consultation as they embark on the perinatal journey. Both groups noted that patient empowerment is dependent on presenting different options and information to patients in order to foster a sense of agency in their treatment and perinatal decisions, as well as hope in what may be possible after treatment. However, providing such support is dependent on patients having better access to information. For example, one provider suggested providing patients with an option for online consultation with lactation specialists. The sentiment expressed by both healthcare providers and community partners was that patients, regardless of how savvy they are, may not know which questions to ask and how best to navigate the perinatal period (e.g., how to find fertility specialists, community programming, support groups). Healthcare providers and community partners become integral in their roles to help navigate the medical system, help determine clarifying questions, and advocate for patient access and knowledge.

It's A Personal Choice in the End^P, H,C^

All stakeholder groups identified that, regardless of healthcare provider, peer, and community input, the choice to pursue pregnancy after BC is a personal one. Ultimately, the patient has to weigh all the information they receive (whether online or from a provider) to decide whether and how they envision their perinatal period. Further, patient decisions may not always align with recommendations they receive from their providers, but patients often find a compromise with which they are comfortable. As one participant stated,

> I know my oncologist and I are a little bit on different pages about how long to breastfeed before going back on the medication… he wanted me to stop breastfeeding at six months. I'm determined to breastfeed until one year before going back on the medication. I know a lot of that for me is about the fact that I was able to conceive so quickly…I will only have been off the tamoxifen for two years total, which very much has an impact on my decision for myself, because I still feel like I'm not putting my health in enough risk to risk her development and her health by stopping breastfeeding earlier than I want to. I mean, I will still be stopping the breastfeed earlier than I want to because I come from a family of people who breastfeed until the baby's done. But one year for me is that good sort of compromise between what he wants and what I want, while not putting too much risk on my health. (P42)

Some YWHBC recognized that their choices were not directly supported by empirical evidence but were still right for them. One YWHBC participant highlighted this conflicting opinion with her oncologist, stating, “my oncologist’s approach to it was essentially like my primary goal is your cancer health and if I had my say, you wouldn’t be having kids. But I can't tell you not to have kids…as a young woman I can't tell you not to do this.” She went on to state that she was provided with the little information that was available but ultimately had to make a choice. She shared, “the information just wasn't there and so we kind of all had to go on hopes and dreams.” (P39)

Healthcare provider participants reflected on the fact that they cannot always offer concrete information and must accept that patients will make their own decisions, even if those decisions are riskier. One provider stated,

> …it's just being comfortable with the unknown and just letting patients know that it's a theoretical risk, but there's no way for us to quantify this. So, it becomes personal judgment based on what's more important to you at that time… (H15)

Another provider acknowledged that it can be difficult to present patients with the risks but that, at some point, the decision is out of the providers' hands.

> My feeling about that is that's an extremely personal decision… And it's kind of hard sometimes… to say, you know, it's ultimately [up to] you and your family, your partner…personally to make a decision about how you would manage if essentially you had a child and then possibly could die of breast cancer…You know I think that's the hard discussion to have … [but] I'll support the woman, what she decides. But like, that's a very personal choice. (H01)

Finding Support and Normalcy

Each participant group highlighted the need for community engagement, to help support patients throughout the perinatal period. Community care helps to empower patients, while also bridging gaps in care when patients may be between healthcare providers. Finding supportive spaces for patients to discuss having children after BC, whether that be a doctor's office or online forum, is integral in bolstering both physical and mental health. This category attempts to define ways in which all stakeholder groups have carved out, or observed how support is built and the implications of such support for YWHBC in the perinatal period.

Seeking Community**[P, H, C]**

All participants noted the important role that online communities play in offering social and emotional support, as well as education, which helps patients navigate from cancer treatment into the perinatal period. As noted above, being without community during this time can leave patients feeling isolated and distressed. Having a space to express concerns about their health, expected physical changes, and postpartum challenges was highlighted as a necessary resource for these YWHBC. While there were no dedicated community programs for YWHBC in the perinatal period, some YWHBC participants had joined Facebook groups (e.g., Babies After Breast Cancer), that offered a safe space to find support as they transitioned into the perinatal period.

In addition, many YWHBC noted that they turned to online groups for the majority of their information gathering when navigating conception into the perinatal period through anecdotal experience of others who had given birth after BC. Many YWHBC participants also mentioned the relief they felt knowing that other women had safely made it through pregnancy. Community partners may play a particularly important role in helping patients navigate online forums and peer groups and connecting them with others (even one or two people) who have been through similar experiences. Social media platforms seem to have become the ‘go to’ resource for patients beginning to navigate this unique time and provide a platform that can normalize their experiences and quell anxiety.

The search for community is well evidenced by community partners who are regularly in contact with YWHBC who are in the perinatal period and can speak to the unique benefits that patients can find from connecting with one another. As one community partner stated,

> If they're navigating something around pregnancy after breast cancer, I don't know if necessarily someone might be looking for a more medical answer or a recommendation to a new doctor or something like that, but I think, more so, what that person's looking for is other people who are in the same boat because it's so isolating… and that's something else that the blogs and storytelling helps do is have a more permanent space for people to share their stories in more detail through storytelling, and then we share those on Instagram and it kind of helps facilitate a conversation and again helps people not feel so alone and then they go off and connect with each other. (H07)

Finding Those Psychosocial Touchstones $^{\mathbf{P,\ H,\ C}}$

Just as community support is necessary, so is one-on-one care. All groups noted the importance of having one or two trusted 'people' with which to share their experience, ask questions, and be a source of stability throughout the perinatal period. Given there are very few dedicated groups or resources for this population, patients may find such support in similar peers to seek solace from isolation and uncertainty during perinatal period. They may also turn to community liaisons to find 'buddies' with whom to pair up.

In addition to peer support, stakeholders identified the role of trusted healthcare providers or community partners who may become like a touchstone for patients throughout their perinatal trajectory, regardless of their area of expertise. For example, many women identified that their family doctor became their main point of contact as they navigate out of the cancer domain into the perinatal domain. These 'touchstones' serve a different purpose than providing information, but offer a sense of safety and security, fulfilling the role of emotional support for patients.

Finally, all participants expressed the difficult emotional experiences common for YWHBC such as uncertainty, fear, frustration, guilt, and shame after BC treatment and during the perinatal period. Each group noted the positive impact of having psychosocial support to help make sense of their experience and develop coping strategies in times of distress. Those YWHBC participants who had engaged in, or been provided with psychosocial support noted the integral role it played in their trajectory in helping to better navigate the perinatal period, just by being able to speak candidly about their experiences. Community organizations may play a large part in filling this role when patients do not have access to private care as they may offer groups that address grief, loss, and trauma. However, given limited resources, YWHBC noted that they often did not have ongoing access to individual psychological care.

Putting Words to Experience$^{\mathbf{P,\,H,\,C}}$

Throughout the analysis there was a general emphasis placed on the importance of hearing stories from other women who had given birth after BC. YWHBC participants noted that they found comfort both in hearing others speak about both their successes and struggles (e.g., difficulties with conception that ultimately resulted in healthy birth). They identified that hearing success stories helped to offset feelings of fear and uncertainty and foster hope for the future. Specifically, when stories came from women with similar experiences (e.g., same cancer type, age, fertility issues). Community organizations noted the importance of co-creating content and narratives that are accessible for YWHBC and can facilitate storytelling and sharing between YWHBC who have questions and concerns about having children after BC. While there may be some apprehension about sharing success stories with peers (as evidenced in the category 'fertility guilt'), many participants expressed that such stories offered hope, regardless of whether they had begun to embark on that journey. One community partner noted that personalizing the experience helps to give confidence to patients, stating, "It gives people hope too you know… to see somebody else have success afterwards. Gives them the confidence to even ask the question." (C07). One YWHBC participant noted that hearing others' experiences were helpful for her in finding hope. She shared,

> It would be helpful even just to have someone just talk about their experience because I know that so many people that have gone through treatment and fertility, there are so many variables and so many differences in everybody's experience. But if you could have just like someone sharing and like one piece of that experience relates to you in some way, and then you can kind of feel like you're not [alone]. (P13)

Dedicated Space for KidsABC $^{\mathbf{P,\,H,\,C}}$

Finally, each stakeholder group was adamant about the importance of having dedicated spaces (online or otherwise) to address the topic of 'kids after breast cancer.' YWHBC have limited choices in terms of support groups and expressed feeling as if they had difficulty finding information and supportive spaces that captured their experiences in a way in which they felt supported. Similarly, healthcare providers and community partners stated that many of their patients lament not having specific information, often feeling isolated in their experiences of navigating the perinatal period after BC treatment. Perhaps counterintuitively, YWHBC participants indicated that taking part in support groups that broadly address the 'survivorship' period (e.g., life after BC) can feel *more* isolating as existing supports often provide general information that are not specific to KidsABC. Therefore, there is an increasing need for a dedicated space to address issues specific to YWHBC who are in the perinatal period (e.g., physical changes in pregnancy, fertility guilt, breastfeeding) that allows a forum to learn and share questions and concerns.

Discussion

The current study aimed to better understand YWHBC, provider, and community partner perspectives regarding the perinatal period after BC. Specifically, we were interested in extant knowledge, questions, and concerns that arise for these stakeholders. Our aim is to use these data, in conjunction with our scoping review, to help design an online educational tool to address participants' informational needs, and bolster communication to improve continuity of care and patient empowerment. As such, interview and focus group content was analysed to identify gaps and needs for each group. The study, therefore, draws upon stakeholder experience, as well as professionally informed observations of the landscape of 'kids after breast cancer.'

The traumatic nature of a cancer diagnosis has long lasting impacts that extend into the survivorship period. Evidence suggests that young women with a history of breast cancer (YWHBC) are particularly vulnerable to mental health challenges after primary treatment, commonly presenting with increases in anxiety, depression, and fear of cancer recurrence (Niedzwiedz et al., 2019, Crist & Grunfeld, 2013). The second most cited concern for YWHBC is family building (Hu et al., 2019; Goncalves et al., 2016). It is well established in the literature that a history of BC impacts women's ability to become pregnant (e.g., gonadotoxic impact of treatment) (Hartnett et al., 2018) but does not exclude women from becoming pregnant. Although low compared to the general population, 3-8% of women give birth after primary BC treatment (Lambertini et al., 2021). The ability to become pregnant and carry to term after BC is a testament to the ever-evolving landscape of oncofertility and standardized practices in the field (e.g., fertility preservation prior to treatment) that aid in supporting patients' future goals as a core piece of BC treatment planning. While promising, many YWHBC report increased distress post-treatment as a result of informational gaps (Khajoei et al., 2023; Vanstone et al., 2021). The current study builds upon the understanding that a lack of access to information leaves YWHBC in limbo post-treatment and contributes to increases in distress such as low mood, anxiety, and fear of recurrence (Hu et al., 2019). Furthermore, not only do YWHBC report a lack of informational resources, but providers also cite that they feel ill equipped and are often unwilling to counsel on matters of fertility and pregnancy due to limited knowledge (Khan et al., 2022; Warner et al., 2016).

The higher-order themes identified in the current study are indicative of the complex nature of having children after BC, not just for YWHBC, but for others involved in their care. Considerations such as treatment decisions that impact family building, psychological well-being, and the impact of pregnancy on future health all shape the experience of navigating having children after BC. Understandably, YWHBC have a number of questions and concerns that are not always easily answered by those involved in their care.

Many of our findings were consistent with previous research. In particular, participants spoke to the fact that cancer history may increase distress in the perinatal period. For example, certain experiences during pregnancy, such as being deemed high-risk, returning to medical settings for testing, and receiving routine breast exams and screening can trigger anxiety and fears of recurrence (Koch et al., 2013; Simoneli et al., 2017). Such emotional distress experienced by YWBC, as noted above, is well documented in the extant literature. However, one novel finding from this study was how many YWHBC experience feelings of ‘fertility guilt’ after becoming pregnant, which may further isolate them from the cancer community. YWHBC participants spoke about the fact that they engaged in cancer support groups beyond their primary treatment but often disengaged from the community after becoming pregnant due to feelings of guilt that others in the group were unable to become pregnant. Community partner participants noted that they rarely encounter pregnant women in community support groups, and that ‘fertility guilt’ may be a factor in some women’s disengagement. Knowing that women may remove themselves from the cancer community after becoming pregnant (yet still be struggling themselves) is an important finding as it may help to guide future program development targeted to this population. Studies show that YWBC often feel isolated and distressed when they are unable to engage in programming that support their specific needs (Ahmad et al., 2015). Thus, it is reasonable to assume that YWHBC who are pregnant or postpartum may also experience similar distress.

Similarly, stakeholders point to the importance of support networks that can address unique concerns experienced by YWHBC. While the need for support networks is well established in previous research (Yufe et al., 2025), our study highlights one important aspect of supportive care resources, likely provided by community groups that help to bridge care in the interim of transition from being a cancer patient to a pregnant woman. Each participant group noted the importance of access to peers, providers, and community programming that support patients’ specific needs (e.g., breastfeeding after BC), recognizing that these needs change over time depending on the stage that women are in. Many existing programs are set up to support the broad community of YWBC and are thus unequipped to address specific needs. The lack of tailored support was identified as a source of distress as women are left in the perinatal period without access to care and information. Each participant group highlighted the need for an informational resource that is responsive to changing needs over time and can help support women through the gaps in care that may be an unfortunate consequence of medical system failures (e.g., waiting for specialist referrals).

Another interesting finding was women's focus on physical health and physical cues that they may be healthy enough to become pregnant (e.g., one woman spoke of the resumption of menses as an indicator that it would be possible to become pregnant). We posit that focusing on physical health provides a focused way of taking back control after treatment. The benefits of such a focus would be twofold. First, focusing on physically strengthening one's body in preparation for potential pregnancy. Second, psychologically reclaiming one's relationship to one's body following the deleterious impacts of cancer treatment on women's body image and embodied experience (e.g., breast disfigurement, weight gain, hair loss, sexual challenges etc). Two important theories may help to explain such behaviour. The first theory, Uncertainty Tolerance (UT) finds that individuals faced with life-threatening illnesses such as cancer are likely to respond either negatively (e.g., avoidance) or positively (e.g., information seeking) to the ambiguity of future outcomes (Hillen et al., 2017). Those who engage in 'positive coping' have improved psychological outcomes (Hillen et al., 2017) and may be able to discern what is within their control in the face of uncertainty. For example, YWHBC who proactively seek out information regarding how best to support their physical health may be doing so as a way of healthy coping after BC treatment.

The second theory, Health Locus of Control theory (Wallston et al., 1976), may help to explain YWHBC's proactive health behaviour. Individuals who have a higher internal health locus of control believe they have agency over the outcome of their health and actively engage in behaviours to support their health. Those who have an external health locus of control believe that their health outcomes are determined by outside forces (e.g., fate, luck) (Mozafari et al., 2024). Thus, YWHBC who are versed in navigating healthcare systems, seeking information, and identifying what is within their control (e.g., XYZ) may be more likely to have an internal health locus of control and actively engage in health behaviours they believe support current and/or future pregnancy.

Moreover, previous studies suggest that women often experience an increase in distress in response to the end of treatment (Schnipper, 2001). More specifically, research has proposed that the absence of focus on ‘getting better’ through intensive medical treatments leads to more in-depth processing of the existential considerations that accompany having cancer (Costanzo et al., 2007). Thus, it follows that YWHBC may find relief in shifting their focus from cancer-related considerations to becoming healthy enough to conceive. One study even suggests that learning they are able to have a child may help relieve worry, as it signals to YWHBC that they are in ‘good health’ (Ahn & Jan, 2023). Our findings suggest that YWHBC commonly inquire about yoga, supplements, and diet that may help support their recovery. Thus, it may be important for future studies to investigate the link between focus on physical health, motivation for pregnancy, and distress relief in YWHBC.

It was the primary author’s assumption that healthcare provider and community partner participants, while both wanting to support patient needs, would identify different questions and concerns, and perhaps even disagree about how to best support YWHBC into the perinatal period. However, the analysis showed to the contrary that all stakeholder groups are generally aligned in their vision of patient care for YWHBC. Moreover, healthcare providers and community partners both recognize the necessity for a diversity of resources, more consistent access to healthcare, and alternative support into the postpartum period (e.g., access to milk banks). This finding is promising in that stakeholders’ goals may work in tandem with one another to better support patient care into the perinatal period. For example, improved communication between healthcare providers and community groups may help bridge gaps in care for patients potentially waiting for specialized referrals. Further, healthcare providers and community partners expressed concern for women’s ability to access care, recognizing structural inequities that they are trying to address in their own practices and in the community setting. Future studies and resource development may be helpful to specifically support communication (e.g., linking provider and community organizations) for information sharing and program development. This direction would accord with recommendations stemming from a recent, combined scoping review and environmental scan of hospital and community-based resources available to YWBC in English-speaking regions (Yufe et al., 2025).

Resource Development

Given that the ultimate goal of this dissertation was resource development, we found several interesting themes related to participants’ vision for an interactive online tool. One interesting higher-order theme was “On the Clock” where stakeholders identified the complex nature of decision-making for patients who wish to become pregnant after BC treatment. For example, decisions made pre-treatment may impact post-treatment family planning (e.g., ability to breastfeed). Therefore, an important element that stakeholders identified for an online tool was interactive content such as updated resource lists, access to providers in the community who can answer specific questions, and other women’s stories of navigating pregnancy after cancer. One patient even suggested the idea of a “buddy system” where patients are matched with peers who have achieved post-cancer pregnancy who may act as mentors throughout the cancer trajectory and perinatal period. Patients, in particular, noted that including these specific elements would better help to make informed decisions throughout the entire treatment trajectory and into the postpartum period, rather than being presented with information more specific to one timepoint.

By doing so, patients are presented with empirical research that enable them to ‘read ahead’ in a sense, to set expectations and better plan for their futures.

Another participant suggested including ways to ‘pin’ information that they deemed relevant to revisit at a later time. The utility of interactive resources is also supported in the literature. One study found that health anxiety may decrease after engaging with interactive education interventions for women with birth anxiety (Derya et al., 2021). Similarly, another suggested that provider counselling plus the introduction of an informational resource (physical or digital) helped to ease distress and increased participants’ retention of health information (Philippe et al., 2022). Thus, providing participant groups with an interactive tool that can help educate and organize information may act as an intervention in and of itself. With the increase in available health technology, younger patient cohorts have become more engaged with their own health care, and more empowered to navigate these technologies, taking on the role of managing their care (Lober & Flowers, 2011). Implementation science literature supports the finding that interactive content is being used more frequently in educational resources (Darnell et al., 2017) and is more likely to help reduce psychosocial distress through building connection and open communication (Wickramaratne et al., 2022).

Limitations and Future Directions

One major limitation of our study is that we were unable to speak with a wider variety of healthcare providers. As stated, the majority of providers were nurses and surgeons working in the area of oncology. While they represent an important provider population, future studies should focus on including fertility specialists and OB/GYNs to better understand the full scope of questions and concerns raised for YWHBC in the perinatal period. Additionally, it would be useful to speak with more community partners to have a better picture of the state of program development for YWHBC, especially as research focuses more on family building into survivorship.

Another limitation is the narrow demographic representation of our patient participants. Diversity is an important consideration when embarking on research in order to be able to accurately represent the landscape of experience and challenges faced by a variety of YWHBC. It is important to recognize that all but one of our YWHBC participants lived in North America and had relatively good access to health care. Whereas one YWHBC from South America noted that access to robust and trustworthy informational resources are lacking in her community. Furthermore, the majority of our YWHBC participants identified as White and were highly educated. Although an important perspective, studies show that women who identify as Black, Latina, and Indigenous generally have less consistent access to healthcare and show poorer health outcomes, both in terms of breast cancer and pregnancy (Yedjou et al., 2020, Maxwell et al., 2024). Despite our best efforts to recruit diverse populations through social media, we were not successful. Therefore, it will be crucial for future studies to intentionally recruit participants that represent a more intersectionally diverse perspective (e.g., ethnicity, socioeconomic status, education) in order to better understand challenges and gaps in care for YWHBC. Finally, it is important to acknowledge the aspect of gender within our sample. While all of the YWHBC participants identified as ‘female,’ I recognize that the terms historically used around birth and breastfeeding are ever-shifting (e.g., person who is pregnant, ‘chest-feeding’) in an effort to better understand the experience of pregnancy after breast cancer for individuals who may not identify as cis-gender women. It will be important for future studies to use inclusive language as it pertains to the participants and directly ask about gender identity and experiences related to breast cancer and pregnancy and/or chest-feeding to better encapsulate the experience of having ‘kids after breast cancer’.

The goal of the current study was to collect data to better understand the questions, concerns, and needs of YWHBC who are in the perinatal period. It is our hope to use these findings to develop an online education resource to help support YWHBC, as well as healthcare providers and community organizations who are directly involved in their care. In general, the transition from ‘cancer patient’ to ‘expecting mother’ is fraught with uncertainty and the potential for increased anxiety. This may be especially true for women who live in remote areas, or who are further out from their treatment. Each participant group spoke to the gaps in care that exist for YWHBC in the perinatal period and the importance of having resources to help bridge these gaps. For example, women are often not referred to an OB/GYN until their second trimester and may rely on their oncologists or general practitioners for information regarding their pregnancy. While we hope that access to up-to-date and accurate information helps to reduce a significant amount of distress, the work to bridge gaps in care and communication must be ongoing. Increased access to information and communication channels for all stakeholders involved in patient care will be integral for navigating the perinatal period for YWHBC. Thus, in designing this resource, we will also be targeting providers and community partners to support their own learning and knowledge translation on the topic. Additionally, a particular young woman’s health care providers may not have direct communication with those from other specialties she is accessing, and medical records may not be updated or available between medical institutions (e.g., urban oncology centres to rural obstetrics practices). These barriers to inter-disciplinary care and communication represent a major disservice to patients who must continue to expend energy coordinating their own care.

Conclusion

The current study undertook a thematic analysis to better understand and address the needs of patients, healthcare providers, and community partners as YWHBC navigate the perinatal period. Each subgroup of participants offered a unique perspective about 'kids after breast cancer' that enabled a more fulsome understanding of the landscape of informational and supportive care for YWHBC in the perinatal period. Providers spoke broadly about practical and medical issues (e.g., considerations of screening, radiation impact on breastfeeding), community partners were more concerned with systemic issues (e.g., costly procedures being prohibitive for patient population access to fertility) and supportive resources, and patients spoke eloquently to the psychological ramifications of inadequate informational and support resources on this topic. Patients also provided insight into the lived experience of the perinatal period after primary BC treatment and creative ways to help better support others through this time. In conjunction with the scoping review (Chapter 2), the current analysis lays the foundation for the development of an online, educational tool that will provide participant groups with up-to-date empirical information, interactive resources, and supportive care resources. We hope that such a resource will bolster stakeholder communication, fill gaps in care, and minimize patient distress, ultimately moving toward an evolving person-centered model of care for YWHBC who wish to and become pregnant.

Final Conclusions and Future Steps

Young women with a history of breast cancer (YWHBC) are at a disproportionate risk of psychosocial challenges as they navigate the survivorship period (Ahmad et al., 2015). The second most cited source of distress for this group, after psychological needs, is family building (Hu et al., 2024). Past research has generally focused on fertility issues for YWBC (Ruddy et al., 2014), but emerging research is now beginning to shift focus to the perinatal period (conception up to 5 years postpartum) for YWHBC. This direction is appropriate given the great strides that have been made in oncofertility for YWBC in recent years (Hong et al., 2023). However, such advancements on their own are only the prologue to the full pregnancy story and need to be accompanied by comprehensive, evidence-based post-conception supports for YWHBC. Therefore, the aim of this dissertation was twofold. The goal of study one was to present the landscape of research related to the perinatal period after BC through a scoping review of the literature. Studies identified included the safety of pregnancy (e.g., rates of recurrence) and pregnancy outcomes for sub-groups of YWHBC (e.g., BRCA carriers), the impact of assisted reproductive technology (ART) for YWHBC, and postpartum concerns such as screening and breastfeeding. These data are necessary to help tailor medical counselling as well as community programming to YWHBC. For example, only recently are studies beginning to highlight the impact of factors such as genetic mutations (BRCA 1 and 2) (Lambertini et al., 2020, 2024), hormone positive disease (Partridge et al., 2023), and outcomes related to time to pregnancy after diagnosis (Labrosse et al., 2021). The goal of study two was to conduct a thematic analysis to better understand the questions, concerns, and informational needs of YWHBC, as well as those involved in their circle of care – their healthcare providers and community supports. The thematic analysis both confirmed previous research (e.g., distress regarding pregnancy, barriers to care, lack of supports) in addition to uncovering participant perspectives regarding knowledge consumption and decision making. Although fortunate that YWHBC who go on to become pregnant have garnered more attention in the research arena, access to empirical evidence and programs to help ease distress and uncertainty is scarce. In fact, YWHBC cite that the lack of information regarding the perinatal period after BC treatment is a source of stress (Vanstone et al., 2021) and may increase anxiety, depression, and fears of cancer recurrence (Wang et al., 2020).

Thus, the ultimate goal of both studies combined is to use the findings to guide the development of an online educational tool to help ease the burden of distress that YWHBC cite due to lack of accessible information. While YWHBC may be savvy in finding information online and express a preference for online supports (Owen et al., 2004), there is some evidence to suggest that they struggle to efficiently navigate the healthcare system, and report increased distress as a result (Rethink Breast Cancer, 2015). Thus, developing an online tool that provides access to trusted and easily digestible evidence-based information is a necessary step in helping to bolstering patient care. Such a tool is supported by international guidelines for YWHBC (Paluch-Shimon et al., 2022), suggesting that online programs and support groups have a direct, positive impact on physical and psychological health outcomes. Additionally, supporting patients to take control of their own health by providing increased access to information and support shows improved health outcomes, as well as improved quality of care from providers (Bailo et al., 2019). Thus, developing this tool not only helps ease distress for the patient population, but may also lead to improved health outcomes for YWHBC.

Further, it is not just the patient population that identified the vast informational gaps related to ‘kids after breast cancer,’ but those who are directly involved in YWHBCs care and support over the perinatal period. For example, different care providers are often solely focused on their area of expertise and positioned to provide care during one ‘slice’ of time throughout the cancer trajectory. Those who work in multidisciplinary teams are often the providers who think more broadly outside of their ‘wheelhouse,’ but they are also the ones best able to refer YWBC to appropriate specialists and resources, whereas those who do not may often be unequipped to answer important questions that patients need to address. Thus, the online tool will also be designed to help healthcare providers and community partners better equip themselves with information regarding the perinatal period after BC; acting as a substitute for multidisciplinary care for those who are siloed.

Beyond the necessity of addressing informational gaps, we see this tool as being able to offer connection and supportive care resources. For example, an online interactive website or application could include the integration of a peer support chat feature, personal success stories and videos of YWHBC who have navigated the perinatal period, as well as resources for supportive counselling. Additionally, the tool could eventually include referral sources based on geographical region to help support providers in more remote areas. We see this tool as one that could be evolving both as more programming and care becomes available and perhaps even offering online education sessions or videos. These are just some additional elements that may be incorporated into an interactive online tool and have a more encompassing reach to help address stakeholder needs.

As international guidelines regarding standard of care for YWHBC continue to evolve, so should patient and provider knowledge about how best to support women through the perinatal period. Especially given the nuanced considerations that arise for the population – such as the impact of coming off tamoxifen to become pregnant, and the impact of engaging in IVF (i.e., hormone injections) after having gone through treatment for hormone positive BC. The more stakeholders who have access to such information, the better continuity of care we can provide YWHBC. Doing so also provides space for community partners who help to develop programming outside hospitals to fill gaps in knowledge. Providing both empirically driven resources as well as safe spaces for YWHBC to share concerns, fears, and hopes related to the perinatal period. By providing stakeholders with this knowledge, we hope that YWHBC and those involved in their care feel more confident to discuss these issues, talk through uncertainties, provide guidance and counselling, and minimize patient distress.

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Appendix A – Recruitment Flyers

KIDS AFTER BREAST CANCER

Seeking research participants!

Have you become pregnant or had a baby after your breast cancer diagnosis – or thought about having one in the future?

We are looking for volunteers who have completed breast cancer treatment to share their experiences and questions concerning pregnancy and postpartum. We hope this will help us create useful resources for individuals who are considering a future pregnancy.

Study details & participation:

1. Complete an online questionnaire
2. Participate in a 60-75 minute focus group over Zoom
3. Provide input on an online educational tool (if interested)

Who is eligible to participate?

- Individuals who are 45 years or younger who have completed surgery, radiation (and/or chemotherapy if applicable) for breast cancer **AND**
- Individuals who can read and speak English
- Individuals who are actively trying to have a baby **OR**
- Individuals who are currently pregnant or *were* pregnant **OR**
- Individuals who had a baby within the last 5 years

***$25 Amazon Gift card for participating**

Contact:
Ruth Vanstone
ruth.vanstone@sunnybrook.ca
416-480-6100 ext. 81447

KIDS AFTER BREAST CANCER

Seeking health care provider research participants!

Do you work with women who have a history of breast cancer?

We are looking for healthcare providers who currently work with young women (45 years and younger) who have completed breast cancer treatment. We are interested in hearing your experiences, questions, and concerns that arise regarding pregnancy and postpartum after breast cancer treatment. We hope this will help us create useful resources for women who are considering a future pregnancy.

Study details & participation:

1. Complete an online questionnaire
2. Participate in a 30 minute focus group with other women over Zoom
3. Provide input on an online educational tool (if interested)

Who is eligible to participate?

- A Licenced healthcare providers currently practicing in Canada working with young women (45 years or younger) with a history of breast cancer (e.g., oncologists, OB/GYN, fertility, nursing)
- Able to complete questionnaires and interviews in English

***$25 Amazon Gift card for participating**

YORK U UNIVERSITÉ UNIVERSITY

Contact:

Ruth Vanstone
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416-480-6100 ext. 81447

Sunnybrook HEALTH SCIENCES CENTRE

KIDS AFTER BREAST CANCER

Seeking research participants!

Do you work with women who have a history of breast cancer?

We are looking for community stakeholders who currently work with young women (45 years and younger) who have completed breast cancer treatment. We are interested in hearing how your organization supports young women with a history of breast cancer and any questions or concerns that arise. We hope this will help us create useful resources for women who are considering a future pregnancy.

Study details & participation:

1. Complete an online questionnaire
2. Participate in a 60-75 minute focus group with other women over Zoom
3. Provide input on an online educational tool (if interested)

Who is eligible to participate?

- Anyone who works for a community organization
- Community workers who have contact with young women with a history of breast cancer
- Able to complete questionnaires and interviews in English

***$25 Amazon Gift card for participating**

YORK U UNIVERSITÉ UNIVERSITY

Contact:
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Sunnybrook HEALTH SCIENCES CENTRE

Appendix B – Questionnaire and Consent

Kids ABC Patient

Consent form Thank you for your interest in our study. Please click the link below in order to review the consent form. Informed Consent_PT

Current consent y/n Please indicate whether you consent to take part in the study

○ I AGREE AND CONSENT (1)

○ I NEITHER AGREE NOR CONSENT (2)

ID # Please enter the unique I.D. number provided to you by the research coordinator

____

City Please state your city of residence

____

Country Please state your country of residence

____

Birth date What is your date of birth? (month/year)

____

Ethnicity How do you self-identify regarding your ethnicity?

☐ African Canadian (1)

☐ Afro-Caribbean (2)

☐ Caucasian (3)

☐ East Asian (e.g. China,Hong Kong, Korea, Vietnam) (4)

☐ Hispanic/Latina (5)

☐ Indigenous (6)

☐ Middle-Eastern or North African (e.g. Egypt, Iran, Israel, Morocco) (7)

☐ South Asian (e.g. India, Pakistan, Sri Lanka) (8)

☐ Other (please specify) (9)

____

Gender How do you self-identify regarding your gender?

○ Female (1)

○ Male (2)

○ Transgender (3)

○ Non-binary (4)

Education What is the highest level of education you have completed?
If currently enrolled please indicate the highest degree received.

○ Less than high school degree (1)

○ High school degree or equivalent (e.g. G.E.D.) (2)

○ College diploma/certificate (3)

○ Bachelor's degree (4)

○ Graduate degree (5)

○ Professional degree (6)

○ Other (please specify) (8) ____

Relationship status What is your current relationship status?

○ Single, never married (1)

○ In a relationship (2)

○ Married or domestic partnership (3)

○ Widowed (4)

○ Separated (5)

○ Divorced (6)

Living Which of the following is applicable to your living situation?

○ Living alone (1)

○ Living with roommate(s) (2)

○ Living with relative(s) (3)

○ Living with spouse/significant other (4)

○ Living with roomate(s) and child/children (6)

○ Living with relative(s) and child/children (7)

○ Living with spouse/significant other and child/children (8)

○ Other (please specify) (5) ____________________

Children y/n Do you have children?

○ Yes (1)

○ No (2)

Child 1 Please select sex and age (indicate months or years) of you **first child**.

○ Male (1) ____________________

○ Female (2) ____________________

Child 2 Please select sex and age (indicate months or years) of your **second child**.

○ Male (1) ____________________

○ Female (2) ____________________

Child 3 Please select sex and age (indicate months or years) of your third child.

○ Male (1) ____

○ Female (2) ____

Child 4 Please select sex and age (indicate months or years) of your fourth child.

○ Male (1) ____

○ Female (2) ____

Child 5 Please select sex and age (indicate months or years) of your fifth child.

○ Male (1) ____

○ Female (2) ____

Birth complications Have you ever had any health complications during birth or pregnancy? If yes please specify.

Currently pregnant Are you currently pregnant?

○ Yes (1)

○ No (2)

Weeks pregnant How many weeks pregnant are you?

____

Cancer stage Please indicate the cancer stage at diagnosis.

○ Stage 1 (1)

○ Stage 2 (2)

○ Stage 3 (3)

○ Stage 4 (4)

Cancer specifics Please indicate any specifics about your breast cancer diagnosis.

____

Diagnosis Please indicate month and year of diagnosis (__/____ e.g. 05/2015)

Treatment What treatments did you receive?

☐ Surgery (1)

☐ Chemotherapy (2)

☐ Radiation (3)

☐ Hormone therapy (4)

☐ Stem cell transplant (5)

☐ Herceptin (6)

☐ Other (please specify) (7) ____

Q29 Thank you for providing your demographic information. Now we would like to give you the opportunity to add any additional comments or specific questions you have in regards to your experience of working with individuals with a history of breast cancer who are in the process of conceiving, or are in the perinatal period.

Comments What are specific issues or concerns that you have encountered with conception, pregnancy, and/or postpartum after breast cancer? (Point form comments are welcome).

Q52 Please indicate whether you consent to being re-approached by the researcher in the future to gauge your interest in providing input into the educational tool that we are developing for this project.

○ I AGREE AND CONSENT to have my contact information used by the researcher to be re-approached with the opportunity to provide input into the development of the online educational tool that will be developed. (1)

○ I NEITHER AGREE NOR CONSENT to have my contact information used by the researcher to be re-approached with the opportunity to provide input into the development of the online educational tool that will be developed. (2)

Kids ABC Provider

Consent form Thank you for your interest in our study. Please click the link below in order to review the consent form.   Provider consentform

Current consent y/n Please indicate whether you consent to take part in the study

○ I AGREE AND CONSENT (1)

○ I NEITHER AGREE NOR CONSENT (2)

ID # Please enter the unique I.D. number provided to you by the research coordinator

____

City Please state your city of residence

____

Country Please state your country of residence

____

Birth date What is your date of birth? (month/year)

____

Ethnicity How do you self-identify regarding your ethnicity?

- ☐ African Canadian (1)
- ☐ Afro-Caribbean (2)
- ☐ Caucasian (3)
- ☐ East Asian (e.g. China,Hong Kong, Korea, Vietnam) (4)
- ☐ Hispanic/Latina (5)
- ☐ Indigenous (6)
- ☐ Middle-Eastern or North African (e.g. Egypt, Iran, Israel, Morocco) (7)
- ☐ South Asian (e.g. India, Pakistan, Sri Lanka) (8)
- ☐ Other (please specify) (9)

____

Gender How do you self-identify regarding your gender?

- ○ Female (1)
- ○ Male (2)
- ○ Transgender (3)
- ○ Non-binary (4)

Education What is the highest level of education you have completed?
If currently enrolled please indicate the highest degree received.

○ Less than high school degree (1)

○ High school degree or equivalent (e.g. G.E.D.) (2)

○ College diploma/certificate (3)

○ Bachelor's degree (4)

○ Graduate degree (5)

○ Professional degree (6)

○ Other (please specify) (8) ____

Q30 What is your area of specialty?

☐ Fertility (1)

☐ OB/GYN (2)

☐ Oncology (3)

☐ Nursing (4)

☐ Other (please specify) (5)
____

Q31 How long have you been practicing?

____

Q16 Thank you for providing your demographic information. Now we would like to give you the opportunity to add any additional comments or specific questions you have in regards to your experience of treating patients with a history of breast cancer who are in the process of conceiving, or are in the perinatal period.

Comments What are specific issues or concerns you encounter with this population? (Point form comments are welcome).

Q52 Please indicate whether you consent to being re-approached by the researcher in the future to gauge your interest in providing input into the educational tool that we are developing for this project.

○ I AGREE AND CONSENT to have my contact information used by the researcher to be re-approached with the opportunity to provide input into the development of the online educational tool that will be developed. (1)

○ I NEITHER AGREE NOR CONSENT to have my contact information used by the researcher to be re-approached with the opportunity to provide input into the development of the online educational tool that will be developed. (2)

Kids ABC Community

Consent form Thank you for your interest in our study. Please click the link below in order to review the consent form.   IFC Community

Current consent y/n Please indicate whether you consent to take part in the study

○ I AGREE AND CONSENT (1)

○ I NEITHER AGREE NOR CONSENT (2)

ID # Please enter the unique I.D. number provided to you by the research coordinator

____

City Please state your city of residence

____

Country Please state your country of residence

____

Birth date What is your date of birth? (month/year)

____

Ethnicity How do you self-identify regarding your ethnicity?

- ☐ African Canadian (1)
- ☐ Afro-Caribbean (2)
- ☐ Caucasian (3)
- ☐ East Asian (e.g. China,Hong Kong, Korea, Vietnam) (4)
- ☐ Hispanic/Latina (5)
- ☐ Indigenous (6)
- ☐ Middle-Eastern or North African (e.g. Egypt, Iran, Israel, Morocco) (7)
- ☐ South Asian (e.g. India, Pakistan, Sri Lanka) (8)
- ☐ Other (please specify) (9) ____

Gender How do you self-identify regarding your gender?

- ○ Female (1)
- ○ Male (2)
- ○ Transgender (3)
- ○ Non-binary (4)

Education What is the highest level of education you have completed?
If currently enrolled please indicate the highest degree received.

○ Less than high school degree (1)

○ High school degree or equivalent (e.g. G.E.D.) (2)

○ College diploma/certificate (3)

○ Bachelor's degree (4)

○ Graduate degree (5)

○ Professional degree (6)

○ Other (please specify) (8) ____

Q31 What services does your organization offer?

Q32 How often do you have direct contact with individuals who are in the process of trying to conceive, are pregnant, or are up to 5 years postpartum?

○ Daily (1)

○ Weekly (2)

○ Monthly (3)

○ Less than monthly (4)

Q33 Thank you for providing your demographic information. Now we would like to give you the opportunity to add any additional comments or specific questions you have in regards to your experience of working with individuals with a history of breast cancer who are in the process of conceiving, or are in the perinatal period.

Comments What are specific issues or concerns that you have encountered working with this population? (Point form comments are welcome).

Q52 Please indicate whether you consent to being re-approached by the researcher in the future to gauge your interest in providing input into the educational tool that we are developing for this project.

○ I AGREE AND CONSENT to have my contact information used by the researcher to be re-approached with the opportunity to provide input into the development of the online educational tool that will be developed. (1)

○ I NEITHER AGREE NOR CONSENT to have my contact information used by the researcher to be re-approached with the opportunity to provide input into the development of the online educational tool that will be developed. (2)

Appendix C – Semi-Structured Interview Guides

Kids ABC (Patient)
Semi Structured Interview Guide

Procedure:
Share with co-host the participants that will be joining and their perinatal status (e.g., pregnant, postpartum, conceiving) and any other important details

Log in and make your co-interviewer co-host

If there are people in the waiting room who are not consented: Send message to waiting room with Ruth's contact info and ask them to reach out about the study if they are interested. Participants have been asked NOT to share the zoom link.

Preamble:

Please remember that this is confidential so if you could change your zoom names to include only first names that would be great. And please do not share other's experiences that you hear today.

Thanks so much for agreeing to speak with me today. And just to remind you, this interview should take approximately 60 minutes and is being audio recorded. As you read in the Consent Form, you should feel free to speak about your experiences only to the extent you feel comfortable, and you also have the option to decline answering any question if that is your preference. In general, we're interested in hearing about your experiences with the perinatal period, specifically the questions and concerns you have regarding pregnancy and postpartum after breast cancer treatment.

I am aware that everyone is busy so I may be more directive in my questions at times so we stay on track and so everyone gets a chance to share.

Housekeeping: if we have any technical issues please log back in if/when you can. If we lose the platform, we will be in touch with you over email asap

Do you have any questions for me before we begin?

1. This is a question about perception - What information were you given about pregnancy after breast cancer treatment and by whom?

2. How was the process of discussing the possibility of pregnancy after treatment had ended? What kind of resources did you have access to?

3. What were/are you most concerned about in the perinatal period (e.g., rates of miscarriage, breast feeding etc.)

4. How did you access information about pregnancy after breast cancer leading up to and during the perinatal period?

5. Were/are your pregnancies considered high risk? If so, how did that change your experience? – what does this mean? In relation to pregnancy or cancer recurrence?

6. What questions would you like to have answered that you may not have had answered during the perinatal period?

7. Did the information you had inform your decisions in the perinatal period? If so, how?

8. How did you find this pregnancy different from past pregnancies (if relevant to the individual)

9. What information would be useful for you to have if you were to become pregnant again in the future?

10. What support systems would be useful for you to have if you were to become pregnant in the future?

11. Breastfeeding? One sided

12. What prompted you to participate?

13. Is there anything else that I didn't ask or that you wanted to add?

If anything else comes up or you want to share something after the focus group please feel free to reach out!

Kids ABC (Provider)
Semi Structured Interview Guide

Preamble: Thanks so much for agreeing to speak with me today. And just to remind you, this interview should take approximately 90 minutes and is being audio recorded. As you read in the Consent Form, you should feel free to speak about your experiences only to the extent you feel comfortable, and you also have the option to decline answering any question if that is your preference. In general, I am interested in hearing about your experiences with women in the perinatal period (or leading up to) with a history of breast cancer. Specifically, your current knowledge and concerns regarding pregnancy and postpartum after breast cancer treatment.

Do you have any questions for me before we begin?

1. Is there specific information that informs how you advise your patients who are in the process of trying to conceive or in the perinatal period after breast cancer treatment? If so, what information is pertinent?

2. Is there up-to-date information that you can access to inform care for patients who are in the process of trying to conceive or in the perinatal period after breast cancer treatment? If so, what information and where is it accessed?

3. Are there any issues that your patients bring to you that you struggle to answer? If so, please elaborate.

4. What would be helpful for you to know in order to improve care for this patient population?

5. Are your patients considered high-risk if they have had breast cancer treatment?

6. What resources do you offer this patient population? (E.g., community resources, therapeutic resources?)

7. How does breast cancer affect breast feeding for this patient population? Are there specific resources for women to access about breast feeding after breast cancer (if applicable)?

Kids ABC (Community)
Semi Structured Interview Guide

Preamble: Thanks so much for agreeing to speak with me today. And just to remind you, this interview should take approximately 60 minutes and is being audio recorded. As you read in the Consent Form, you should feel free to speak about your experiences only to the extent you feel comfortable, and you also have the option to decline answering any question if that is your preference. In general, I am interested in hearing about your experiences with clients/members in the perinatal period (or leading up to) with a history of breast cancer. We are interested in hearing specifically about how you're current involved with this population as well as knowledge and concerns that you hear from members or that you have yourselves regarding this population. The ultimate goal is that we hope to create an online education tool, guided by these focus groups and informed by empirical research for providers, members, organizations to use in regards to pregnancy and postpartum after breast cancer treatment.

Do you have any questions for me before we begin?

1. What is your specific role, what do you see as your specific role as working with this population as Rethink?

- What resources do you offer this client population? (E.g., support groups, therapeutic resources?)

2. What types of issues are commonly raised by women who are trying to conceive or are in the perinatal period?

- What has changed over the years?
- Thinking back to those who have become pregnant, do you remember issues that have come up with those clients?

3. Is there specific information that informs how you advise your members/clients who are in the process of trying to conceive or in the perinatal period after breast cancer treatment? If so, what information is pertinent?

4. Is there up-to-date information that you can access to inform care for clients who are in the process of trying to conceive or in the perinatal period after breast cancer treatment? If so, what information and where is it accessed?

- What information are you drawing on to support these women?
- How has that changed over the years?
- Are programs more accessible here?
- What informs your programs?

5. What information would be helpful for you to know in order to improve care for this client population? What would you like to see in an online tool?