I’M SO HAPPY, BUT ALSO TERRIFIED: THE EXPERIENCES OF WOMEN WITH A HISTORY OF CANCER DURING THE PERINATAL PERIOD

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Abstract

Young female cancer survivors are at a disproportionate risk of suffering psychological distress following treatment, particularly fears of cancer recurrence (FCR). While previous research has established the robust relationship between FCR and family matters (e.g., fertility and motherhood), there remains a paucity of information about how a cancer history affects women's psychological functioning throughout the perinatal period. The present investigation sought to better understand women's perinatal experiences following cancer treatment. The study sample was composed of 10 participants who each took part in a semi-structured interview. A grounded theory analysis yielded *I'm So Happy, But Also Terrified*, as the core category, representing the duality of emotions that characterized the perinatal period for these women. Additionally, four higher-order categories emerged from analysis of interview text. Study implications are further discussed to better understand the complexity of these experiences and future directions are suggested for the improvement of perinatal care after cancer.

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Introduction

Cancer Diagnosis and Psychological Distress in Young Adults

In 2020, over 225,000 people will be diagnosed with cancer in Canada alone (Canadian Cancer Society, 2020). Due to medical advancements, survival rates have shown a steady increase, with many survivors expected to live five years or more after a cancer diagnosis (Canadian Cancer Society, 2020). This outcome is especially true for younger populations with the highest survival rates being in those diagnosed between 15 and 40 years of age (Cancer Research UK, 2020). Despite these medical advances, living with a history of cancer often introduces psychosocial challenges well into survivorship. Furthermore, it is well documented that, although young adults comprise a minority percentage of cases, they are at increased risk of experiencing elevated distress as compared to their older counterparts (Christ & Grunfeld, 2013). Neugarten (1976) posits that cancer introduces an unexpected disruption in younger peoples' expected life trajectory, which may impinge on achieving key developmental milestones. Research conducted with young cancer survivors supports that many experience disruptions in education and career advancement, as well as challenges with family planning and fertility (Husson et al., 2018). Clinically, a history of cancer can lead to increased depression and anxiety (Niedzwiedz et al., 2019; Geue et al., 2018; Bergerot et al., 2018), fatigue, cognitive impairment, and pain (Stanton et al., 2015). Among the most commonly cited types of psychological distress that young adults with a history of cancer experience is fear of cancer recurrence (FCR) (Sun et al., 2019), a condition particularly prevalent among young women (Crist & Grunfeld, 2013; Geue et al., 2017; Bergerot et al., 2018).

Fear of Cancer Recurrence

FCR is defined as "the fear or worry that the cancer will return or progress in the same organ or in another part of the body" (Simard & Simard, 2009, p. 241). FCR has been shown to be ubiquitous across cancer type (Götze et al., 2019), and affects a significant proportion of survivors with reported rates of moderate to high levels of FCR ranging from 33%-56% (Lebel et al., 2013). FCR is distinct from anxiety as a trait or disorder and may severely impact mood as well as the ability to plan for the future (Freeman-Gibb et al., 2017; McGinty et al., 2012). It may also lead to attempts to avoid reminders of cancer, or hypervigilance in relation to unfamiliar physical symptoms (Crist & Grunfeld, 2013). In extreme cases, FCR may develop into an anxiety disorder, and/or major depressive disorder (Christ & Grunfeld, 2013). Although FCR is distinct from anxiety, the two constructs are significantly correlated (Götze et al., 2019). One study found that survivors with clinically significant levels of FCR were likely to suffer from a comorbid psychiatric disorder, most commonly an anxiety disorder such as Panic Disorder and Generalized Anxiety Disorder (Simard & Savard, 2015). Moreover, FCR is associated with increased contact with healthcare providers and increased healthcare costs (Thewes et al., 2016). Interestingly, it is more commonly observed in patients receiving hormone replacement therapy, chemotherapy, and/or radiation treatments compared to surgery alone (Götze et al., 2019). There is, however, evidence to suggest that post-treatment FCR may be mediated by the patient's symptom control and satisfaction with treatment (Crist & Grunfeld, 2013).

Unfortunately, although it is a significant problem for many survivors, the identification and treatment of FCR may be difficult given that it is not often a persistent worry but one that occurs in relation to specific situations such as routine follow-up care or the anniversary of diagnosis or, often unexpectedly, in relation to media triggers such as news stories or when movie or television characters are stricken with cancer (Koch et al., 2013). Additionally, FCR may persist over a long period of time, with survivors reporting FCR over 10 years after treatment (Simard et al., 2013; Koch et al., 2013; Christ & Grunfeld, 2013). Of particular relevance to the current investigation is the fact that higher severity of cancer-related distress, and FCR in particular, is significantly more common in young women than young men (Lane et al., 2019; Lebel et al., 2014).

Fear of Cancer Recurrence in Young Women

The majority of past research regarding cancer related psychosocial distress has been limited to breast cancer (Freeman-Gibb et al., 2017; Lebel et al., 2013), however, there is evidence that this gender difference is consistent across cancer types (Bergerot et al., 2018; Geue et al., 2017; Christ & Grunfeld, 2013). While research regarding young women's psychosocial functioning is still emerging, there is evidence that specific periods of life may increase women's vulnerability to FCR distress. For example, women who are actively engaged in family planning show elevated levels of FCR (Armuand et al., 2018). One recent study on FCR in breast cancer patients reported that women may worry specifically about the possibility of passing down cancer genes to their children (Wan et al., 2018). In addition, higher levels of FCR have been observed in women with children, citing mothers' concern regarding the emotional impact that a recurrence would have on their family members (Lebel et al., 2013). For example, women worry about the disruption that a recurrence would have on their family life, as well as the economic burden that would be placed on their spouse and children should they die prematurely (Götze et al., 2019). However, despite the robust relationship between FCR and family matters (e.g., family planning, motherhood), there is a paucity of information detailing how a history of cancer affects a woman's experience of pregnancy, and specifically how cancer-related anxiety, and being currently or recently pregnant, interrelate. The present investigation seeks to elucidate these experiences and how they affect women's psychosocial functioning.

Treatment-Related Fertility Concerns

An additional challenge unique to women is their ability to conceive and bear children following cancer treatment. Many young female survivors express the wish to have biological families and, in fact, this wish may even become more pronounced after treatment (Waimey et al., 2015). However, women often worry about whether pregnancy is safe or even possible, and these concerns are not unfounded given that cancer treatments may impede a women's reproductive ability (Hartnett et al., 2018).

There are multiple ways that cancer treatments may interfere with reproduction depending on whether the treatment is systemic or focal, and the body part being targeted by the treatment. Chemotherapy, for example, is recognized to be gonadotoxic, especially in high dose alkylating agents (i.e., drugs which damage the cancer cell DNA to prevent copies), resulting in an exponential decline in healthy oocytes (i.e., immature egg cells) and, thus, lowering the potential for viable pregnancy (Roberts et al., 2015). Additionally, chemotherapy may disrupt female hormone production, causing premature menopause and long-term amenorrhea (loss of menstruation) (Waimey et al., 2015). On the other hand, radiation therapy may be especially damaging to reproductive health when directed at the abdomen or pelvis, often resulting in oocyte damage (Waimey et al., 2015). Radiation may also damage the endometrium (the innermost lining of the uterus), which can lead to later miscarriage, mid-trimester pregnancy loss, preterm birth, and low birth weight (Waimey et al., 2015). Similar to chemotherapy, high levels of cranial irradiation can cause hormonal disruptions, which negatively impact fertility (Waimey et al., 2015). For women with ovarian, endometrial or cervical cancers, surgery, removal of the tumour via radical trachelectomy (removal of the cervix), hysterectomy (removal of the uterus) and/or bilateral oophorectomy (removal of the ovaries), may render women unable to reproduce naturally (Waimey et al., 2015) even though the surgery itself is less aggressive than other treatment options. Finally, Selective Estrogen Receptor Modulators (SERMs) such as Tamoxifen, are another standard of care treatment used for hormone-sensitive breast cancer taken for five to 10 years after treatment to extend longevity in premenopausal women. Although hormonal therapies have been shown to improve survival rates, it is recommended that they not be taken during pregnancy due to teratogenic effects (disruption to embryo or fetal development) (Shandley et al., 2017). Thus, understandably women may struggle with the decision to discontinue a lifesaving treatment in order to become pregnant.

However, despite the potentially damaging effects of treatment, there is preliminary evidence that becoming pregnant after cancer treatment is relatively safe. For example, there is evidence that women who are able to become pregnant after treatment for breast cancer do not show an increase of recurrence and, in fact, pregnancy after breast cancer, in one study, lowered risk of death by 41% (Carneiro et al., 2018). Additionally, despite earlier concerns within the medical community, pregnancy for women with hormone receptor positive breast cancers does not appear to increase risk of death (Carneiro et al., 2018).

Given the physiological toll that cancer treatment can have on women's reproductive system, fertility is often cited as one of the greatest concerns for women of childbearing age both at diagnosis and after treatment (Waimey et al., 2015), and may influence women's decision-making in regard to treatment. Some women may even deny receiving certain recommended treatments due to their aggressiveness and potential to severely limit their chances of becoming pregnant (Campbell-Enns & Woodgate, 2017; Goncalves et al., 2016). For example, Senkus et al. (2014) found in a sample of breast cancer patients that 8% refused chemotherapy in order to preserve fertility but were more inclined to do so if the benefit of chemotherapy was likely to be low.

Studies have also shown that there is very little information provided to women regarding pregnancy after cancer (Ameri et al., 2018; Azulay et al., 2020), and young women consistently report a lack of resources and healthcare provider support regarding fertility (Campbell-Enns & Woodgate, 2017; Ameri et al., 2018). In one study of female patients 18-40 years of age, conducted in California, many did not recall any discussion regarding fertility options before the beginning of treatment and only 5% were referred to a fertility specialist. This lack of communication was particularly pronounced for women who were single (Gonçalves et al., 2016). Women also reported dissatisfaction with their discussions with health care providers regarding the impact of their treatment on reproductive health and expressed wanting to be informed as soon as possible after diagnosis about their options (Gonçalves et al., 2016). In fact, those who reported having received adequate information regarding fertility options showed reduced levels of psychological distress and reproductive regret as compared to those who did not receive this information (Mahajan, 2015).

Several studies examining health care providers attitudes toward oncofertility have found several reasons for a lack of communication regarding fertility options. For example, one study conducted with Canadian breast cancer surgeons reported that they did not believe it was their responsibility to initiate fertility conversations with their patients, did not know of fertility clinics in their area, and were unfamiliar with fertility preservation options (Warner et al., 2016). A quantitative study regarding oncology physician behaviours for adult cancer patients conducted in China revealed similar results, citing that physicians felt they lacked the knowledge to discuss oncofertility with their patients (Zhang et al., 2019).

Despite these shortcomings, health care providers may be in a difficult position to counsel patients as there remains a lack of evidence of the longitudinal effects of cancer treatment on fertility, thus, leading to inconsistent guidelines regarding how to proceed after treatment. For example, Matthews et al. (2012) cite that remaining oocytes after cancer treatment have likely survived due to a lack of carcinogenic effects from treatment. However, healthcare provider guidelines still suggest delaying conception for at least six months after chemotherapy, and at least 12 months after radiation to minimize risk to the fetus (Matthews et al., 2012). Other literature suggests that women should wait 12 months after chemotherapy treatment in order to ensure that any damaged oocytes are cleared from the body to reduce the risk of miscarriage and birth defects (Hartnett et al., 2018). This recommendation stemmed from findings that the risk of preterm birth and low birth weight was higher in women who underwent chemotherapy and/or radiation therapy and conceived within one year of concluding treatment - results that were consistent across cancer type (Hartnett et al., 2018). Another study suggested that waiting two or more years after the end of treatment is ideal to ensure the best outcomes (Connell et al., 2006). With respect to breast cancer specifically, there is evidence suggesting that there is a higher risk of recurrence or metastasis for women diagnosed within five years of childbirth (Wan et al., 2018).

While there is no evidence that pregnancy (Buonomo et al., 2020) or breastfeeding (Azulay et al., 2020) increases the risk of recurrence, women may still experience heightened psychological distress both when considering becoming pregnant, and during pregnancy. More recent studies report significant FCR when women engage in family planning (Arumand et al., 2018), during pregnancy (Azulay et al., 2020), and into motherhood (Ares et al., 2014). Specifically, women note 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 (specifically after breast cancer) (Connell et al., 2006; Azulay et al., 2020).

Pain After Cancer

Adding to women's distress is the occurrence of pain after cancer. Following cancer treatment, it is common to experience new physical sensations and changes. However, the presence of these sensations often promotes increased attention to these symptoms, which may heighten FCR. For example, pain may be interpreted as a threat depending on an individual's cancer history, which may increase attentional bias, fear and worry (Cho, Chu, & Lu, 2018). Heathcote and Eccleston (2017) state that after treatment, many cancer patients have the urge to diligently monitor symptoms in order to 'get ahead' of metastasis or recurrent diagnoses. However, such checking may also prime patients for attending to different or altered sensations, including pain. Furthermore, survivors who experienced a significant degree of pain during cancer treatment and who experience their current pain as threatening may be at increased risk for FCR, specifically if they do not have adequate information about managing their pain (Kelada et al., 2019).

This relationship between pain and FCR may be further complicated by pregnancy. The perinatal period (commonly defined as the period from conception to one year postpartum) is characterized by physiological and psychological changes that put the body in flux (Agrati et al., 2015). If women are already hypervigilant about changing bodily sensations due to their cancer history, they may be even more likely to attend anxiously to various aches and pains that are otherwise normal during pregnancy, especially if they have never been pregnant before. For example, breast pain and benign breast lumps are a common occurrence during pregnancy and lactation (Teberian et al. 2019) but may be especially worrisome for women with a history of breast cancer. Additionally, Cooklin et al. (2018) report that 90% of women experience at least one symptom of physical pain within eight weeks of giving birth, and, if persistent, can lead to an increase in depression and anxiety. Given that some women with a cancer history are already prone to over-attending to physical sensations in order to reduce FCR distress (Soriano et al., 2019), this tendency may be exacerbated during pregnancy and the postpartum period, leading to an increased risk for anxiously attending to 'normal' physical symptoms.

Perinatal Anxiety

Even without a history of cancer, there is evidence that women may have heightened anxiety during pregnancy, with the incidence of anxiety disorders during pregnancy reported at 15% (Bayrampour et al., 2018). Approximately 23% of women report some form of anxiety throughout the perinatal period (Bayrampour et al., 2018) and up to 20% of women meet criteria for an anxiety disorder within their first year postpartum (Furtado et al., 2018)[1]. Unfortunately, recent research has shown that perinatal anxiety can significantly impact the mental and physical health of both mother and child including fetal distress, preterm birth, increased admission to neonatal ICUs, low birth weight (Bayrampour et al., 2018), pre-eclampsia (a complication in pregnancy indicated by high blood pressure and damage to other organs), miscarriage, increased postpartum depression (Fairbrother et al., 2017), and increased physical symptoms (Furtado et al., 2018). Children of mothers with heightened anxiety may also experience negative consequences well into toddlerhood. For example, studies of neurological risks in infants with

[1] Note: Women in the general population are more likely than men to develop an anxiety disorder over their lifetime. Women ages 18-34 are most likely to develop Social Anxiety Disorder (SAD) or Generalized Anxiety Disorder (GAD) (Bandelow & Michaels, 2015). 12-month prevalence rates for women of all ages report the highest rates for specific phobia (15.7%) and SAD (15.5%), while GAD is reported at 6.6% (McLean et al., 2011).

anxious mothers report slowed neuromotor development at three months (van Batenburg-Eddes et al., 2009) and slowed hippocampal growth at six months (Qiu et al,. 2013), as well as an increase in ADHD risk up to seven-years-old (Fairbrother et al., 2107). These risks are prevalent not only for women who meet criteria for severe anxiety disorders, but also for women who have elevated anxious symptoms during pregnancy (Bayrampour et al., 2018).

Women may also experience increases in anxiety due to previous pregnancy loss, lack of adaptive coping, and a history of mental illness (Martini et al., 2016; Bayrampour et al., 2018). Additionally, pre-existing anxiety and depression put women at increased risk for pregnancy-specific anxiety, such as fear of pain during birth and fears about the newborn child's health, both of which increase likelihood of adverse outcomes (Martini et al., 2016). In particular, previous loss of pregnancy may increase anxiety and fears surrounding the health of the fetus during pregnancy (Bayrampour et al., 2018; Martini et al., 2015). Women who have had a previous pregnancy loss demonstrate up to 2.5 times higher rates of pregnancy-specific anxiety than those who have not (Bayrampour et al., 2018). Of particular interest is the fact that women who are considered to have high risk pregnancies (defined as an increased risk for maternal and/or fetal complications) were more likely to develop an anxiety disorder - specifically, generalized anxiety or obsessive-compulsive disorder (Fairbrother et al., 2017).

Present Study

Given the prevalence of FCR and pregnancy-related anxiety among female cancer survivors on the one hand, and the adverse consequences for both mother and child in women who experience general perinatal anxiety on the other, it is important to understand how a history of cancer may impact women's psychosocial distress during the perinatal period. Of particular concern is that the susceptibility to experiencing comorbid FCR and anxiety may put pregnant cancer survivors at increased risk for adverse mental and physical health outcomes both during and after pregnancy. To date, only one study has examined the psychological impact of cancer during the perinatal period, but this study focuses specifically on breastfeeding and is limited to a breast cancer population (Azulay et al., 2020). Therefore, very little is known about the lived experience of a cancer history during this unique stage of a woman's life. Specifically, there remains a paucity of understanding of the psychological complexities that such a history may introduce into an already vulnerable period in a woman's life thus warranting further exploration of the issue.

By better understanding women's experiences of pregnancy after cancer it may also be possible to increase resources provided to women during this unique time. As past research has shown, women report a lack of support and resources surrounding fertility (Gonçalves et al., 2016; Ameri et al., 2018), as well as pregnancy and breastfeeding during and after cancer (Azulay et al., 2020). Despite representing a small proportion of pregnant women, there is ample evidence that young women with a history of cancer are in need of unique support and increased services (e.g., fertility, psychosocial support) which may extend far beyond the end of their treatment (i.e., because they continue to go through various life stages after cancer that now become more complicated to navigate due to their history).

The aim of the present study was to understand women's experiences of the perinatal period after having received treatment for cancer. We were particularly interested in the role that pregnancy may play in eliciting or triggering FCR, which would in turn increase anxiety experienced throughout the pregnancy. We were also interested in the ways in which women coped, both physically and emotionally, during their pregnancies and into the postpartum period, and how they dealt with navigating a healthcare system with sparse information related to their unique maternal trajectories. Finally, we were interested in how women perceived their healthcare provider support in the transition from cancer treatment into pregnancy, and other sources of support that they found helpful throughout the process.

Given the lack of extant information on women in the perinatal period with a history of cancer, we chose to conduct a qualitative investigation. The inductive analytic approach used in the current study permitted an understanding of the phenomenon of interest to emerge based on women's lived experiences of navigating pregnancy after cancer. Furthermore, a qualitative analysis may allow us to speak more broadly to the improvement of care and quality of life from the perspectives of those individuals receiving care. Although young women who become pregnant after cancer represent a small proportion of survivors, they are at a disproportionately high risk of psychosocial distress. Thus, it is imperative to more fully understand women's unique experiences during the perinatal period after a history of cancer in order to ensure adequate care for both mother and child.

Research Questions and Objective

The objective of this study is to better understand women's subjective experiences of pregnancy after cancer - in particular, their experiences related to anxiety and FCR. In this vein, the study will address the following research questions:

1. How does a history of cancer impact women's experiences of pregnancy?
2. What additional challenges have women encountered due to their cancer history? (e.g. their experience with health care resources)
3. Were there periods over the course of their pregnancy that were more emotionally or physically difficult than others? If so, what made them more challenging?

Method

The study protocol was reviewed and approved by the Research Ethics Board (REB) of the Sunnybrook Health Sciences Centre (REB #344), and the York University Human Participants Committee prior to participant recruitment. Informed consent was obtained from all participants before any data were collected.

Participants

The sample was composed of 10 women. Inclusion criteria were as follows (1) past cancer diagnosis (across cancer type); (2) no active disease or treatment; (3) 45-years of age or younger; (4) currently in the perinatal period; and (4) the ability to read and speak English fluently. Although recruitment was world-wide (as per below), 90% of participants resided in Canada. The average age of the participants was 35.4 years. All women were in a heterosexual relationship and living with their partner. Only one of the ten women had children prior to their cancer diagnosis. Four women were currently pregnant, and six women were between 2.5 to 10 months postpartum. Of the four pregnant women, none had any children. Of the six postpartum women, one had only 1 child. The sample was primarily Caucasian (60%), with one East Asian participant (10%), one Middle Eastern participant (10%), one mixed-race participant (10%), and one South Asian participant (10%). Overall, 40% of women had an undergraduate university degree as their highest level of education, 10% of women had a professional degree, and 50% of women had completed a graduate degree. In terms of medical characteristics, the majority of participants had been diagnosed with non-Hodgkin's lymphoma and breast cancer (see Table 1). Four of the ten participants underwent procedures for oocyte cryopreservation (egg freezing) and one became pregnant by in vitro fertilization (IVF) using her frozen eggs, while the other three were able to conceive naturally. Two of the ten participants received medications to help preserve fertility during cancer treatment. Of the six women who were in the postpartum period, half gave birth via cesarian section due to complications during pregnancy or birth (see Table 1).

Table 1

Participant disease and pregnancy characteristics

		n (%)
Cancer Type		
	Breast	6 (60)
	Non-Hodgkin's lymphoma	3 (30)
	Leukemia	1 (10)
Cancer Treatment		
	Surgery	6 (60)
	Chemotherapy	9 (90)
	Radiation	3 (30)
	Herceptin	2 (20)
	Hormone Replacement Therapy	2 (20)
Fertility preservation		
	None	4 (40)
	Oocyte cryopreservation	4 (40)
	Goserelin or Leuprolide	2 (20)
Method of conception		
	Naturally	9 (90)
	IVF	1 (10)
Method of birth		
	Natural	3 (30)
	Cesarian section	3 (30)

Procedures

No conflicts of interest were identified. Participants were primarily recruited (80%) through advertisements placed on online cancer support websites across North America and Europe or social media subsites dedicated to cancer survivors (e.g., Reddit), the remaining participants were recruited through their primary care providers (oncology) at Sunnybrook hospital. Interested individuals contacted the study coordinator by email or phone to confirm that they met inclusion criteria. Once criteria were confirmed, each participant was sent a consent form via Qualtrics and, upon consent, an interview was scheduled.

Data collection consisted of semi-structured interviews with each participant to gain a better understanding of women's experiences of the perinatal period after cancer diagnosis and treatment. Specifically, the interviews focused on women's emotional experiences and coping efforts in relation to the various challenges they faced during both cancer and pregnancy and (where applicable) postpartum. An additional area of interest was women's access to fertility and perinatal resources given their history of cancer. Examples of questions included: "How was the process of discussing the possibility of pregnancy after treatment had ended?" and "How do you think your experience of cancer has affected your pregnancy (if at all)?" (see Appendix A for the full semi-structured interview guide). All interviews were conducted by R.V.

In total, 10 interviews were completed over the course of 5 months from March 2020-July 2020. Time since diagnosis for the participants ranged from 1.5 to 9 years. All interviews were conducted via telephone, except one held via Zoom version 5.0.2, a secure, online videoconferencing platform. Interviews were audio recorded. Interview length averaged 55 minutes. The interviews were guided by a semi-structured interview guide, leaving the interviewer the option to pursue alternate avenues of questioning based on participant responses that were unique to their situation. Consistent with qualitative methodology, data collection and analysis were conducted simultaneously thus allowing the opportunity to add questions to the interview guide as necessary based on themes that emerged during the interviews.

Analysis

This study employed a grounded theory analysis, first proposed by sociologists Glaser & Straus (1967), and subsequently adapted for use in psychology by Rennie, Philips, & Quartaro (1988). Grounded theory allows for the data to guide the development of an emergent theory by using an inductive approach during the initial phases of coding interview text, and subsequently, a deductive approach wherein the emerging categories are analyzed together as a whole data set (Henwood & Pidgeon, 2003). This method helps to ensure that the analysis is reflective of the data, rather than driven by predetermined theoretical concepts. Additionally, grounded theory allows for the co-construction of understanding through a merging of the participant's and the researcher's 'horizon of understanding' (Gadamer, 2004). The mere act of engaging in conversation with the goal of arriving at a mutual understanding allows for the co-construction of a new reality, which thereby contributes to a deeper understanding of the phenomenon in question (Rennie, 2000).

All interviews were audio recorded and transcribed *verbatim*. Each interview was divided into excerpts of text, referred to as 'meaning units' (MUs) (Giorgi, 1970) - each of which represented a single theme or concept. Each MU was then assigned a category label representative of the essential idea or ideas contained within it. The constant comparison method (Glaser & Strauss, 1967) was applied such that each new MU was compared to existing categories. If none of the codes adequately captured the theme or concept being expressed in the MU, a new category was created. In some instances, existing categories were re-named in order to more adequately capture and integrate the new data. This process continued until no new categories emerged from the data, thus reaching saturation. Saturation was reached after analysis of the ninth transcript. By using this constant comparison technique, we ensured that the theory was grounded in the data. Ultimately, 54 lower-order categories resulted from this process.

Once the transcripts were coded, a hierarchical structure was created by grouping together categories with a shared meaning element. Lower-order categories were organized such that each grouping of codes was indicative of a newly created, higher-order category. This process continued until one ‘core’ category was constructed to capture the phenomenon of interest, representing the full data set.

The creation of higher-order categories was guided by our broader research question of whether and how women with a cancer history experience psychological distress during the perinatal period as a result of this history. Thus, this analysis was both inductive and deductive in nature. As is standard in the grounded theory method, the researcher recorded memos throughout the categorization process. Such memos reflected potential connections to extant theory, perceived inter-relationships among the codes, new ideas regarding the interplay between cancer and pregnancy, and insights into women’s experience derived from the data. Thus, the memos helped with both understanding and organizing the data. Additionally, throughout the analysis, validity checks were performed by Dr. Fergus by reviewing emerging categories. Discrepancies in category creation were discussed until an agreement was reached.

As per Glaser and Straus (1967), data collection and analysis were conducted simultaneously and concluded when no novel categories emerged from the data, and additional data did not produce new categories (Givens, 2016). Given this was a convenience rather than theoretically derived sample (Glaser & Strauss, 1967), the type of categorical saturation achieved in this context was bounded by the fact that this was an educated relatively socio-economically advantaged sample of women with access to universal health care. Categorical saturation was reached after nine interviews, although a tenth interview was conducted to ensure we had passed the point of saturation. This is consistent with literature stating that as many as 10 interviews may be necessary to uncover more nuanced codes in the data if no new codes emerge from three consecutive interviews (Francis et al., 2009).

Rennie (2000) states that in order to achieve a deep understanding of the text, there is no way to understand the phenomenon which you are analyzing without employing a subjective lens and embracing of one's own subjectivity. By the same token, it is necessary to make one's known assumptions explicit so that the reader can discern for themselves the extent to which the grounded theory adequately represents the phenomenon rather than the researcher's a priori understanding (Rennie, 2000). Relatedly, an effort was made to approach the data by being as open and curious as possible so as to allow new theory to emerge from the text (as opposed to previously held beliefs about the phenomenon).While it is always the goal of grounded theory analysis to set aside one's biases when evaluating the text, it is important to acknowledge that the researchers' interpretation of the data were necessarily shaped, to a degree, by their previous knowledge of the phenomenon (e.g., oncology, perinatal anxiety), as well as their personal beliefs and hypotheses regarding the psychological impact that cancer may have throughout the perinatal period. In particular, RV believed that women would be particularly anxious during the perinatal period given their cancer history, which may lead to complications in pregnancy. This presupposition was likely driven by RV's work in the field of perinatal anxiety and PTSD prior to undertaking this study. Furthermore, we expected that women with a history of cancer would anxiously attend to 'normal' changes in their bodies due to pregnancy and that their appraisal may be anxiously misconstrued as a sign of recurrence. Also top of mind entering into the analysis was the extant literature on the prevalence of fear of cancer recurrence in young women, as well as regarding women's mental health vulnerabilities during pregnancy.

Epistemologically, we approached the analysis from an interpretive phenomenological framework - that is, attempting to understand how a phenomenon presents itself by reflecting upon both the researcher's and participant's subjective experience, while also acknowledging that this experience is subject to broader social, cultural, and psychological influences (Willig, 2012). This approach to interpretation is more acknowledging of the role that researcher subjectivity plays in the design, collection and interpretation of research data as compared with a more objectivistic or realist orientation which presumes that the researcher is able to maintain absolute objectivity throughout this process. In doing so, the researchers recognize that both they, and the participants held their own subjective interpretation of participant's experience, which helped to more deeply understand the phenomenon.

Results

The grounded theory analysis resulted in a total of 43 lower-order codes, which were subsequently organized into nine higher-order categories. These nine higher-order categories represent the defining features of the four main categories, from which a core category emerged, *"I'm So Happy, but Also Terrified"* representing women's experience of the perinatal period after cancer. The core category was reflective of the finding that women in the perinatal period experience a concurrent duality of emotions, uniquely influenced by their history of cancer.

The experience of being happy but terrified was quite consistent among the participants. All of the women felt a sense of elation with being able to become pregnant, the intensity of which was amplified by their cancer history and, in particular, the fact that many of them thought they may never have had the opportunity to conceive. However, for the majority of women, their experience of elation was coupled with an intense fear, stemming from cancer-related worries specific to each woman's experience. For example, some women worried in general about cancer recurrence due to the limited time between the end of treatment and the start of pregnancy. One woman worried whether ceasing to continue taking Tamoxifen in order to become pregnant would cause a recurrence. Others worried about passing cancer genes on to their children.

Despite individual differences, every participant's experience of pregnancy after cancer included at least one element of the following (representing the four main categories): (1) *Preservation of Hope*, in which participants expressed a narrative of grieving the possible loss of fertility but finding hope in the measures taken for fertility preservation before or during cancer treatment; (2) *Joy Shaded by Worry*, wherein participants expressed conditional joy while pregnant and, in some cases, into the postpartum period, unable to embrace their excitement due to worries of recurrence and the health of their child; (3) *Conceiving of a New Future*, which represented women's frustration with the lack of information regarding fertility options during and after cancer treatment, and the steps they later took to ensure they had the best possible healthcare team throughout their pregnancy journey; and (4) *Shedding My Cancer Body*, in which women expressed that, although cancer would always be a part of their narrative, pregnancy seemed to define a boundary between the two experiences of cancer and motherhood. These four higher-order categories are summarized in Table 2 below. In the following presentation of the findings, quotations have been chosen to illustrate the categories, and labelled in brackets with the participant's unique ID number, and age.

Preservation of Hope

Mourning the Possible Loss of Fertility

Every participant (n=10) expressed that the potential loss of fertility was very salient to them after receiving their cancer diagnosis. As one woman said, "I think that was one of the first things that came to mind at that point, 'Would I ever be able to have kids?'" (P012, 29). It was extremely difficult to try and process that the future they had planned for, which included the dream of having children, might not be possible, especially as they were simultaneously processing their cancer diagnosis. The majority of women (n=8) expressed that the idea of the potential loss of fertility was devastating to consider and, in some cases, even more devastating than the cancer diagnosis. As one woman said:

> I was I think grieving this possibility of 'Oh we were gonna start a family right away [and] now we can't.'…That was harder for me. I was sad that maybe we won't be able to have kids, or we won't for five years or you know, we don't know if it will even be possible… (P013, 38)

Table 2

Higher-order categories and their defining properties

Higher-Order Categories	Defining Properties	n (%)
Preservation of Hope		
	Mourning the loss of fertility	10 (100)
	Fertility preservation as hope for the future	7 (70)
Joy Shaded by Worry		
	Lingering reminders of cancer	9 (90)
	Conditional joy	9 (90)
	Counting down the milestones	6 (60)
Conceiving of A New Future		
	Informational vacuum	10 (100)
	Finding the ones you trust	8 (80)
Shedding My Cancer Body	Trust your body	8 (80)

This loss was particularly difficult to come to terms with as women felt that their diagnosis had derailed their plans for the future. One woman, who had been told that she would never be able to conceive again, stated, “We were like, ‘I guess we're just going to have a family of three, not a family of four’ - It's not what we wanted, not what we planned” (P006, 37). Another woman recalled, “The whole fertility aspect of course was also really devastating because that year, um, when I was diagnosed, my husband and I were going to be starting to try to have a baby that year” (P015, 35). Some women (n=7) also recognized that the loss of fertility would impact their future quality of life. It was as if they were having to choose between their present life and their potential future, having to make a decision without knowing the interlacing impact that both fertility and cancer treatments would have on their bodies. One woman speaking to this, said:

> I was very afraid of what the fertility medications would do in terms of affecting the cancer-recurrence… I think my surgeon at the time that they saw [me] they didn't… think it would pose a risk-and I just wanted to have children so bad that, I, I needed to know that I could do everything that I could. (P010, 41)

Another piece of the devastation was dealing with the uncertainty of the effect of treatment on fertility. The majority of women (n=9) struggled with the fact that they were unsure of whether treatment would result in infertility and found it difficult to process the ambiguity of a potential loss. One woman said she felt as if the “cards were stacked against me” (P006, 37), and others expressed that, although they were unsure of the outcome of treatment, they felt as if they still had to come to terms with the loss of fertility. This upset was compounded, for some women (n=4) by the fact that they had no support around coming to terms with the possible loss of fertility. Many viewed their healthcare providers as more concerned with their present health as opposed to their future quality of life.

Fertility Preservation as Hope for the Future

Although the idea of fertility loss was distressing for women, it was juxtaposed with the hope offered by the opportunity for fertility preservation. The majority of women (n=7) expressed that they viewed fertility preservation as providing a sense of control throughout their cancer treatment as well as hope for the future. As one woman said of freezing her eggs, “I'm not closing this door, I'm keeping the door open to the possibility of having children” (P001, 40). Other women (n=4) said that merely going to see a fertility specialist and better understanding their options greatly helped their coping. One woman said of speaking about the possibility of having children in the future, “It is something that I always wanted to do and so knowing that there were options in that regard helped me to just feel as though I had a bit of control over that aspect of that treatment” (P014, 37). Another woman said:

> I feel grateful that I had the opportunity to end up freezing some eggs. I didn't end up using them but it was, like, actually quite helpful for me in terms of coping…to know that cancer wasn't taking that away from me, you know, it was still an option. (P001, 40)

Another woman spoke of trying to decide whether to participate in a fertility study:

> I went through so much in decision[-making], so many struggles just trying to decide if I wanted to go ahead with participating [in] the trial and taking a break from my medication. And it’s almost like going through that decision process allowed me, once I made the decision, to put it aside if that makes sense… I really didn’t struggle with a lot of anxiety stress around cancer-related things during pregnancy. If anything, I think it

gave me something to be excited about and it really helped me to move forward. (P014, 37)

Although only four women were able to actually freeze their eggs, others expressed that simply knowing this was an option afforded them a feeling of control while in treatment.

Joy Shaded by Worry

Lingering Reminders of Cancer

The majority of participants (n=9) experienced cancer triggers throughout their pregnancy. For example, one woman spoke about finding a lump in her armpit during pregnancy, where she had found her cancer, “I was 14 weeks pregnant, and, so it's like, you go down the deep dark hole again… you're instantly back to where you were the first time” (P006, 37). Another woman stated that even going for ultrasounds was distressing due to their negative association with breast imaging. Other women (n=2) had negative thoughts about giving birth in the hospital as hospitals elicited memories of treatment. One woman said, of touring the hospital in preparation for giving birth, “I remember on the hospital tour actually just bursting out - like I had to leave and was just in tears, I was like ‘I can't do this I don't want to have a hospital birth’... they're [hospitals] filled with fear” (P001, 40).

Other women (n=6) expressed that cancer had primed them to expect bad news throughout pregnancy, which put them on high alert. As one woman said, “You do carry with you, kind of like medical trauma…you kind of get into a mindset that you're always going to receive terrible medical news” (P002, 31). Women felt that cancer would always be a part of their narrative that would carry forward into other experiences, colouring other aspects of life.

Conditional Joy

The idea of conditional joy was endorsed by the majority of women (n=9) when speaking about their experience of pregnancy and, in some cases, after giving birth. On the one hand, pregnancy elicited overwhelming joy for the majority of women (n=9) all of whom had thought at some point throughout their cancer journey that pregnancy may not have been a possibility. However, the joy was coupled with various fears, engendered by the experience of cancer diagnosis and treatment. For example, some women (n=4) worried about the lingering effect that chemotherapy may have had on their bodies, such as the possible damage to their eggs and the safety of the fetus in a post chemotherapy body. As one woman articulated:

> For me it was like 'Well what if… what if the quality of my eggs has been compromised because of chemo? So what if there's um, you know, potential for, genetic diseases?' All of these terrible things were kind of my initial thoughts. So it was that happiness of like, 'Oh my god it happened and like we really weren't expecting it to, but then that constant fear of something will go wrong. (P007, 31)

Others were explicitly worried about their cancer returning, "You're so overjoyed about this baby, but then you're terrified that your cancer is going to come back" (P006, 37) and, for women who had been diagnosed with hormone-receptor positive breast cancer (n=4), the effect that hormonal changes in their body would have on their health. One woman stated:

> In the back of my mind there was still the little piece of fear and there's also knowing that I'm off my cancer medications and I have all this estrogen in my body now, and you worry about, um, doing harm to yourself… (P015, 35)

Others mentioned their worries about passing on cancer genes to their children (n=6), which for one woman, elicited questions about her own motives for pregnancy, "I really wrestled with the fact that knowing I had cancer I was choosing to bring a child into the world and, you know, is that selfish?" (P001, 40). Similarly, another participant, upon reflecting on the possibility that she may carry the BRCA1 gene, worried about her level of responsibility in passing it on to her children, stating, "On the one hand, I understand that it is not something I can control. On the other hand, it is something I can control because I'm passing it on" (P003, 35). These women expressed that they wanted their children to be safe and healthy, to have a 'fighting chance', and said they had feelings of guilt, or selfishness for wanting to conceive and raise children, knowing that they may, at some point in their lives, be affected by cancer.

With only one exception, women expressed a duality of emotions when finding out they were pregnant, which continued throughout pregnancy and, in some cases, into the postpartum period (n=6). Their cautious happiness was always fueled by their history of cancer and represents a complexity of experience that is very unique to these individuals. As one woman said of becoming a mother, "Actually, unfortunately I had to mentally process this, though it gets easier it never completely goes away. Like, the fear never completely goes away" (P014, 37). By the same token, the worry about cancer returning did not overshadow women's joy of being pregnant. Rather, it rendered the joy conditional and subject to moments of worry specific to each woman's cancer history.

Counting Down the Milestones

Pregnancy is necessarily coupled with various milestones, that women looked toward for reassurance of the health of their child. As evidenced above, women contend with many worries during pregnancy and they tended to assuage these worries by seeking healthcare provider reassurance throughout their pregnancy (n=6), and taking comfort in moving predictably (interpreted as safely) from one milestone to the next (n=6). As one woman put it, "Once you kind of clear certain hurdles, you feel a lot better" (P002, 31). In a sense, women felt as if they were holding their breath, hoping to make it safely to the next important milestone.

Participants (n=6) also expressed that the first trimester was especially challenging and one in which they felt they needed extra reassurance that both they and their baby were healthy and safe. This increased reassurance-seeking appeared linked to the experience of having had cancer, which increased worry for their baby's health. One woman said of her routine check-ups:

> [At] every appointment I ask… after every ultrasound, 'Is the baby growing okay, does the baby seem healthy?' I think that's always at the back of your mind. I've had health issues, and is my baby doing okay…During the first few weeks we were happy, but it's like being cautiously happy. (P012, 29)

Several women (n=6), for example, indicated that once they made it past the first trimester, in which the rate of miscarriage is highest, that they felt as if they could exhale.

A similar theme emerged around various genetic testing undertaken throughout pregnancy (n=2). In the words of one woman who had genetic testing done, "I think once you get that bit of reassurance, once you get all those tests done, you do feel a lot better" (P002, 31). One participant in particular sought reassurance in hearing statistics from a trusted healthcare provider. For example, as she progressed through pregnancy, she found comfort in knowing her likelihood of miscarriage and subsequently stillbirth was reduced. She described that knowing the rate of risk, and then passing those milestones acted as a way of gaining control over something that was ostensibly out of her grasp:

> It doesn't look like there's anything related to chemo that is affecting my pregnancy or will affect my pregnancy. For me it's like ok on an individual level…I already googled what the rate of, of stillbirth is...So I already know that they say it's like, it's just below

1% essentially, and it's like… seven out of 1000 births or something like that in Canada. So, I already have that number, but I want to hear it like from the doctor. (P007, 31)

There is an overall tendency to take comfort in the milestones that pass (e.g., after the first trimester rate of miscarriage decreases), to be able to exhale for a period of time. As one woman said, "As the time went on… your stress level sorta goes down cause everything is, still, still healthy, still normal. So, you're just at that cautiously optimistic stage" (P006, 37). Although some worry in pregnancy is likely normal, women with a history of cancer seem especially anxious about reaching these milestones, given the dearth of information on the impact of cancer treatment on pregnancy. This sentiment was reflected in the relief that women felt when being reassured that they had no health complications as their pregnancies advanced.

Conceiving of a New Future

Informational Vacuum

Although each participant was able to conceive after cancer, all expressed some dissatisfaction with the limited amount of fertility information they had access to both during and after treatment. They expressed frustration with this informational void. Some (n=3) identified that there was a general lack of information for women their age. One woman stated, "A lot of the information… out there were for women who had cancer later on in life after they've had kids…That's all the information I could find" (P012, 29). This frustration was compounded by the fact that, as many women (n=5) divulged, even their healthcare providers were not able to provide information - mostly due to lack of knowledge. In speaking with her fertility specialist, one woman commented, "I remember asking about…chemo and how that would affect fertility and him saying, 'You know, I don't really know'" (P001, 40). Another woman reflected on her frustration with the healthcare system. While she said that she felt positively about her care, she found it scary that there was so little information about the safety of pregnancy after cancer. In response, she thought, "'Why can't you give me more answers?!' When you realize how many [i.e., how few]… There literally hasn't been enough women of childbearing age with this type of leukemia to even do a study on this" (P002, 31).

As a result of the lack of information forthcoming from health care providers, participants expressed having to draw on their own resources to gain a sense of understanding about issues regarding pregnancy after cancer. Specific concerns expressed by women in the study were whether IVF (in vitro fertilization) would fuel their tumour growth (n=1), the length of time they should wait after the end of treatment to become pregnant (n=2), and the effect of ceasing hormone replacement drugs (n=1). As one woman put it:

> There's just so much that's unknown about pregnancy in our age group…We had to make some educated guesses about what was best for us, and just spend a lot of time reflecting on a lot of 'what ifs.' And just try to make the best decision that made sense for us with the bits of information that we had" (P015, 35).

Most of the women (n=9) expressed that, because of all the unknowns about pregnancy after cancer, they felt they were left on their own to make potentially life-changing decisions about their future. They commented on how the lack of information about fertility, in particular, compounded the stress of cancer treatment. These feelings manifested both before and after treatment, either when trying to understand their chances of conceiving after cancer, or if successful, the safety of pregnancy for themselves and the newborn.

Additionally, some women (n=4) expressed that they were frustrated by the lack of psychosocial support resources. Although they were able to find cancer-related supports (e.g., cancer survivor networks, support groups, individual counselling), women recounted missing resources to deal with pregnancy after cancer. As one woman said:

> I don't really know that many women who had cancer, or still are living with cancer and then chose to have children. I don't have a lot of those connections and I feel like sometimes I'm seeking them or wanting them…I just don't really have a network of people that I can- can talk to who have a similar experience. (P001, 40)

At some stage, whether seeking information about fertility preservation before cancer treatment, or in thinking about conception after treatment, every woman felt that there was uncertainty and often very little, if any, information they could find as if they were feeling their way in the dark for a light switch that does not exist.

Finding the Ones You Trust

The lack of information on fertility that characterized their experience during cancer treatment seemed to spark a sense of self-advocacy when entering into the perinatal period as women became savvier in navigating the healthcare system and garnering the support they needed. The majority of participants (n=8) spoke about the importance of finding perinatal healthcare providers with whom they felt comfortable. Some women (n=4), spoke of 'shopping around' until they found those whom they felt would give them the best quality of care. For example, when she found out she was pregnant, one woman recalled, "At that point I knew I need to absolutely find somebody I can trust…and with my previous family doctor I didn't really have that relationship. So that's when I made the switch" (P012, 29).

While navigating the perinatal period, women (n=8) expressed that finding healthcare providers whom they trusted was integral to their coping. One woman credits her healthcare team for supporting her through an extremely difficult time during pregnancy, stating, "It made all the difference - like I will forever be grateful to the healthcare team that I had" (P010, 41). Another woman said, of her experience speaking with her oncologist about the future of her fertility:

> It did feel like that was always kind of part of the approach that my oncologist took with me was just kind of understanding that you know that I have things I wanted to do after treatment and I never felt like I was being dismissed and I worry sometimes that women do feel that way and I feel very fortunate that I didn't. (P014, 38)

Some women (n=3) also recalled the importance of self-advocacy throughout the perinatal period. As one woman said of the medical system, "It doesn't have all the answers, so you do need to be your own advocate" (P001, 40). Another woman attributed her ability to advocate for herself throughout the perinatal period to her experience with cancer, as she was able to apply what she learned as a cancer patient to her experience as a perinatal patient:

> I think that there is something that happens to at least a percentage if not all people who go through treatment like you, I don't want to say become an expert at things, but definitely you become a bit more savvy and you learn about what makes you feel more comfortable when you are being taken care of. (P014, 37)

In addition to their oncologists, fertility specialists, and OB/GYNs, several women (n=4) spoke, in particular, about the importance of finding mental health support. One woman shared how her relationship with her counsellor allowed for a certain, and necessary, vulnerability that she did not allow herself with her personal support system (e.g., significant others, family members, or friends). Another participant stated, "I could be that emotional wreck and I could bawl my eyes out for an hour… because she wasn't my family, she wasn't my friends" (P006, 37). It was as if they were given permission to unravel in the moments that they needed to, which was an important piece of coping with the difficulties of pregnancy after cancer. Another woman mentioned that her psychologist helped her become a better advocate for herself throughout pregnancy. She recalls voicing her frustration with her family doctor during a therapy session, and her psychologist remarking, "'Why do you have to stay with someone who makes you feel uncomfortable?' and you know, 'Just keep looking and maybe that will be a positive thing for you'" (P014, 37), which was a turning point for this individual in obtaining the support and guidance she needed to feel more comfortable with her perinatal care. Working with a trusted healthcare provider was integral to helping women navigate the unknowns when trying to become pregnant after cancer.

Shedding My Cancer Body

Trust Your Body

Nearly all participants felt that there was a clear distinction between their 'cancer body' and their 'pregnant body' (n=8), specifically when relating to bodily sensations during pregnancy. For example, one woman stated that, although some symptoms of pregnancy were similar to those of chemotherapy, she was able to distinguish readily between the two and felt no added worry. In fact, two women said that, albeit unpleasant, symptoms of pregnancy such as morning sickness and back pain, were reminders of their ability to become pregnant and were therefore more associated with feelings of joy rather than worry:

> I knew that that feeling wasn't because of chemo, like it was because I was…for such a, happy reason-that I was experiencing it but I didn't even care it was just- I was just elated to be expecting a baby and I knew that these symptoms were part of it. (P010, 41)

Two women expressed that their body gave them "clues" that they were ready and able to conceive. One woman said that, although she experienced morning sickness and back pain during pregnancy, these symptoms were perceived as positive signs of a healthy pregnancy. Similarly, another woman stated that she was optimistic to be still menstruating (after having been through chemotherapy), and felt that it may be a sign of fertility, “I was still getting my periods, so I thought maybe it’s not such a bad thing, as in, it’s not a done deal, as in, ‘It’s not as if I’ll never be able to have children’” (P003, 35).

Women generally expressed that the physical sensations they felt during pregnancy were, for them, instinctively pregnancy related and associated with feelings of joy, rather than worry. Additionally, most women (n=8) could easily distinguish 'normal' pregnancy pains from cancer-related discomfort or pain, despite some symptoms being similar such as nausea from chemotherapy versus morning sickness.

Pregnancy as A New Chapter

Regardless of the undeniable burden that a history of cancer brings, all of the participants (n=10) expressed how fortunate they were to have become pregnant after cancer. For participants, pregnancy felt like a ‘win against all odds’ or as one participant strikingly put it, “the luckiest of the unluckiest” (P002, 31). Another woman expressed that, during treatment, she was determined to take something positive away from the experience, and, for her, that was what pregnancy represented. Of her decision to undergo fertility treatment, she recalled:

> I spent a lot of time weighing the pros and cons and you know we talked earlier about like cancer having power over people and treatment and I just basically said, ‘Enough is enough’ - like I am sick and tired of answering to this disease and you know. (P014, 37)

Some of the participants (n=4) also expressed that cancer helped them gain perspective about what their bodies were capable of. As one woman said:

> I can tell you for an absolute fact that before I had cancer, I thought ‘Oh a childbirth looks excruciating and it looks so painful and difficult’. And I probably feared it but I- I didn't…I was looking forward to meeting my baby and having a baby, and I was just- just so grateful that I could be pregnant. (P010, 41)

There was a sense that getting through cancer prepared the women for other difficult experiences they might encounter throughout the perinatal period. One woman recalls that after her series of cancer surgeries, which left her incapacitated for two weeks, her recovery from cesarian section was relatively easy. She stated, “Then with the C-section it was like I was walking around the unit on the second night that we were there feeling pretty good” (P013, 38).

Not only did the physical feats associated with pregnancy seem easier after cancer, but some women (n=2) also reflected on how the experience of cancer offered some perspective as they embarked on the journey into motherhood. For example, one woman said, “I think as women who've experienced cancer you know, you develop so many skills and tools to navigate the unknown. Of which can be applied to so many other settings, like being a mom” (P001, 40). Another said:

> I think the main effect was not to take it for granted right? Like we might not have been able to get pregnant, we might not have been able to do it at this time, and we did and so it’s maybe more special in that way. (P013, 37)

Some women (n=4) viewed pregnancy as a protective barrier between themselves and the cancer and expressed gratitude for the ability to conceive. They were able to ‘look back’ on the cancer experience and draw a boundary between their perinatal selves and their cancer selves. As one woman reflected, “I'm looking at it from the other end now, like, that I just recently had a baby and I'm just incredibly grateful that- that I could” (P010, 41). Another woman succinctly stated, “I’m pregnant [laughter]. I’m optimistic. I’m more optimistic about the future” (P003, 35).

Similarly, several women (n=6) felt that, although the experience of cancer would never be forgotten, pregnancy represented a new chapter in their lives that helped them move forward, like a light at the end of the cancer tunnel. One woman said of her upcoming breast reconstruction surgery, “Hopefully once the baby’s here, a few months after we can just close the chapter” (P012, 29).

Although cancer is never forgotten, pregnancy represents a hopeful way forward; a way to delineate the dark journey that was cancer, from the possibility of a bright future ahead:

> And just kind of any kind of memories of going through treatment or having those dark times or even remembering when I thought I couldn't have kids or just remembering really difficult aspects of going through the chemo…I would say that I do feel almost more distanced from it now that I'm pregnant and going through this…. chapter… I will view being pregnant as the ultimate symbol of being done with it, I guess. (P002, 31)

Discussion

The present study was conducted in an attempt to better understand how a history of cancer affects women’s experiences of the perinatal period. The diagnosis and treatment of cancer is an exceptionally distressing experience and continues to plague survivors long after the end of treatment. FCR is consistently reported as one of the biggest challenges for cancer survivors (Sun et al., 2019; Simard et al., 2013; Crist & Grunfeld, 2013) and is particularly pronounced in young women (Lebel et al., 2013; Ares et al., 2014). The current study builds on prior evidence that FCR may be related to motherhood. For example, women show elevated levels of FCR when they engage in family planning (Arumand et al., 2018), and during pregnancy (Azulay et al., 2020). Additionally, FCR is observed in mothers who are two or more years postpartum (Ares et al., 2014). However, to our knowledge, the present study is the first to conduct a qualitative investigation into the effects of cancer during the perinatal period. The current study sheds light on how women experience the transition from cancer patient to perinatal patient, their specific worries during pregnancy and postpartum, and how their history of cancer may help to inform them of how best to cope with challenges during the perinatal period.

The core category that emerged from our analysis, I'm So Happy, but Also Terrified, illustrates the complexity of women's experience and the duality of emotional responses that women exhibit during the perinatal period. Our results suggest that women, while excited by pregnancy, also endure long-lasting effects of cancer such as worries about the safety of fertility preservation (e.g., increase in hormones necessary for preservation that may fuel cancer growth in hormone receptor positive women) and pregnancy, and the experience of medical triggers. We found that women sought to cope with the consequences of their cancer history by increasing their own knowledge of perinatal health and seeking support from health care providers whose knowledge they trusted.

The majority of our findings are consistent with previous research. Notably, what was identifiably distressing for each of our participants was learning that cancer treatment may lead to a loss of fertility. Each of our participants revealed that, either at diagnosis or early into treatment, fertility preservation was a major concern and, in fact, that the choice to preserve fertility helped to alleviate their distress during treatment. These findings are consistent with previous research which indicates that fertility preservation is of utmost importance to women of childbearing age who are diagnosed with cancer and who want to have children (Gonçalves et al., 2016). Women report an increase in depression and psychological distress when they perceive a lack of information regarding fertility preservation and in relation to fertility loss (Matthews et al., 2012). Conversely, when women are provided with increased fertility resources and options for preservation, they report increased levels of hope and a greater sense of control throughout their cancer treatment (Tschudin, & Bitzer, 2009; Panagiotopoulou et al., 2018).

Studies have demonstrated that Uncertainty Tolerance (UT) may determine psychological outcomes, both negative and positive, and is especially salient in relation to life-threatening illnesses such as cancer given the ambiguity of future outcomes (Strout et al., 2018; Hillen et al., 2017). Hillen et al. (2017) define UT as "[t]he set of negative and positive psychological responses—cognitive, emotional, and behavioral—provoked by the conscious awareness of ignorance about particular aspects of the world" (pp. 70). Negative cognitive and emotional appraisals of uncertainty may elicit feelings of vulnerability, worry, fear, and anxiety (Hillen et al., 2017). Although such appraisals can lead to negative behaviours such as avoidance, we found that our participants reported to have coped with uncertainty through action and information seeking (both considered positive coping behaviours in the UT model) (Hillen et al., 2017). All but one participant took action to better inform themselves of the risks of cancer treatment on fertility either by speaking to a fertility specialist and/or by accessing online information about fertility preservation. Additionally, seven of the 10 participants took further action to preserve fertility through egg freezing (n=5) or taking temporary protective drugs throughout cancer treatment which help to protect ovaries (n=2). Participants expressed that taking action to preserve their fertility was integral to their coping throughout cancer.

Another key finding was the fact that women felt a conditional sense of joy upon finding out they were pregnant, which extended, in some cases, into the postpartum period. Their sense of excitement at being able to conceive despite their history of cancer co-occurred with lingering reminders of cancer. Women expressed that they experienced increased worry and anxiety regarding the impact that cancer treatment had on their bodies. They also reported an increase in reassurance-seeking toward their healthcare providers during the perinatal period about the health of their child. The first trimester was particularly difficult for the majority of women given the higher rates of miscarriage and several individuals felt that they were continually bracing for bad news at each perinatal check-up. Additionally, three participants experienced heightened anxiety during hospital visits and exams due to negative associations with their cancer history. The experience of such triggers is consistent with extant literature, which suggests that cancer survivors often experience heightened FCR in specific medical situations such as during appointments with healthcare providers, examinations, and other procedures, which can activate negative memories of cancer treatment (Koch et al., 2013; Simoneli et al., 2017).

Additionally, participants expressed intense fears in pregnancy about the effect that cancer treatment had had on their bodies and whether their child would be at an increased risk of health concerns both in utero and throughout their lives. Specifically, women cited fears surrounding the state of their ovaries and eggs post chemotherapy, worries about passing on cancer genes to their children, the safety of pregnancy after cancer, and fears of cancer recurrence. Similar findings are reported in the FCR literature which documents that while up to 92% of cancer survivors report hopes of having children post-treatment, they worry about the effect of cancer treatment on subsequent pregnancies and report heightened levels of fear when thinking ahead to parenthood (Schmidt et al., 2014). Given that past literature also reports heightened FCR for women who are already mothers (Lebel et al., 2013; Ares et al., 2014), it is not surprising that women would worry about these issues during the perinatal period as well.

The one unanticipated finding, based on previous understanding of the interrelationship between FCR and hypervigilance (Crist & Grunfeld, 2013), was the reduction of concern around bodily symptoms reported by this sample of women. We found that, for example, the majority of our participants were easily able to distinguish 'normal' symptoms of pregnancy from past cancer pain or discomfort. This reduction of concern was despite the fact that there were similarities across the two experiences, and that certain aspects of pregnancy were reminiscent of cancer treatment (such as nausea and back pain). Pregnancy, overall, was associated with a positive experience and, therefore, caused no FCR or distress. For those women who did experience FCR, their symptoms (e.g., armpit lump, breast lump) were directly related to their personal cancer diagnoses and delineated from symptoms of pregnancy. While more research is needed, this finding suggests that pain and physiological experiences that normally might trigger FCR may not be at play to as great a degree for a woman while pregnant because the more common symptoms of pregnancy appear to be interpreted as such, as normal physiological changes due to pregnancy.

Another major theme that emerged from our analysis was participants' increased knowledge of the healthcare system after cancer, which sparked, for some, actions related to self-advocacy into the perinatal period. All participants cited a lack of information regarding fertility preservation options before cancer treatments, as well as a lack of information about the risks of pregnancy after cancer. This dearth of pregnancy-related information coupled with the known fertility risks posed by cancer treatment were a pronounced source of distress and frustration for all participants. This finding is not unique. Despite ongoing research regarding both fertility preservation throughout cancer treatment, and the safety of pregnancy after treatment, women continue to report a paucity of information (Carneiro et al., 2018). Thus, the research has not yet met the informational needs of this patient population. Andrykowski et al. (2008) state that access to informational resources is integral to cancer patients' and survivors' well-being and psychological health. Specifically, information that is clearly communicated and well understood.

Interestingly, this lack of information seemed to spark women's proactivity in searching for informational resources (e.g., support groups). Lober & Flowers (2011) observed that, with the increase in available health technology, younger patient cohorts have become more engaged with their own health care. As a consequence, younger cohorts have become more empowered to navigate these technologies in order to assume a more active role in their care (Lober & Flowers, 2011). This phenomenon is evident with baby boomers, and now millennials who have become more knowledgeable and engaged consumers and who, generally, seek out patient-centered care (Lober & Flowers, 2011). This increase in engagement was noted in a majority of our participants, especially in the transition from cancer patient to perinatal patient.

While it is difficult to provide general information for patients given the variability of diagnosis and treatment, the women in our study reported that increased contact with their trusted health care providers was integral to their coping with pregnancy and into the postpartum period. This not only included oncologists, OB/GYNs, and family doctors, but also mental health professionals throughout the perinatal period. Women prioritized finding trusted and reliable health care providers and expressed that in the instances in which their health care providers proactively engaged in conversations regarding their perinatal health, including sharing recent studies about the effects of cancer treatments on fertility, and the safety of pregnancy after cancer, they were better able to cope with cancer related worries.

The finding that the active engagement participants played in their perinatal care may have been driven by their experience in cancer care accords with Richardson's concept of 'resilient reintegrations.' Richardson (2002) posits that resilience develops as a reaction to disruption in one's life and subsequent growth that is guided by the experiential knowledge acquired through that disruption. This process of evolved reintegration may help in coping with subsequent life events so that they become routine rather than distressing (Richardson, 2002). This phenomenon in relation to resiliency was also evident in the current study in the way that most participants seemed to draw upon their cancer experience to inform them about the care they needed to cope during the perinatal period.

The importance of personal social support is well established in the cancer (Illingworth et al., 2010) and pregnancy (Elsenbruch et al., 2007) literature, and is shown to positively influence coping. While women in our study each mentioned the importance of partner and family support throughout the perinatal period, they indicated that their relationship with their healthcare provider was paramount to their coping as they were women's primary source of information. Early work by Mollman et al. (1984) found that cancer patients rely on health care support and contact to reduce illness related uncertainty. Similarly, Meggiolaro et al. (2015) found that patients who perceived their healthcare provider to be disengaged and unsupportive reported higher levels of distress and hopelessness. A review conducted by Arora (2003) found that positive patient-physician communication in cancer populations is indicative of patient well-being and patients who view their healthcare provider as supportive and knowledgeable show better health outcomes. Our findings reflect this literature and, perhaps, add the nuance that women who have been through cancer are better positioned to self-advocate for increased healthcare provider support during the perinatal period due to their increased awareness of their own needs when in care.

Finally, participants in our study reflected on the fact that, while cancer would never be forgotten, pregnancy represented a new chapter in their lives. Each woman stated that she was more appreciative of her ability to conceive due to the fact that she had been through cancer treatment which jeopardized this very capacity. Taylor and Lobel (1989) introduced the notion of downward social comparison - that is, comparing oneself with others who are perceived to be worse off - as a form of coping with life-threatening illnesses. They identified that cancer patients in particular often unconsciously use ‘downward comparison’ as a strategy to cope with threatening aspects of cancer. Similarly, patients used ‘upward’ social comparison techniques to derive hope. Though we did not explicitly explore whether our participants compared themselves to others, we found that they seemed to rely upon a form of *internal* downward comparison, by which they compared their pregnant selves to their prior cancer selves, as a way of feeling more secure about the future. Several women, for example, were able to identify that pregnancy, as a reflection of their wellness/good health, provided a way to move toward a more hopeful future, describing the experience as a “new chapter,” one separate from cancer. Interestingly, in this way, pregnancy may act as a protective factor as women are able to delineate these two experiences; seeing themselves as having distanced from cancer, they were more able to integrate an optimistic narrative, buffering them from the potential threat of their cancer history.

Although there is no research, to our knowledge, addressing the psychological effects of cancer in the perinatal period, HIV literature suggests that pregnancy may similarly act as a protective factor for women who are HIV positive (Vescovi et al., 2014). In keeping with the present study’s findings, Vescovi et al. (2014) report that although HIV positive women felt guilt and fear when reflecting on the potentially negative health consequences they might pass on to their child, pregnancy also represented a 'normal' life stage that women found motivating and hopeful. Therefore, it is possible that women with a history of cancer also experience pregnancy as signifying of health in how the body, as being able to perform 'normal' female functions, bolstered their feelings of hope for the future and, thus, their ability to cope with the challenges of survivorship.

Implications

Coping with cancer is extremely difficult for young women who show disproportionate rates of psychological distress, namely FCR (Simard et al., 2013; Crist & Grunfeld, 2013; Lebel et al., 2014). FCR is particularly pronounced in women who are engaging in family planning (Armuand et al., 2018) and for women with children (Lebel et al., 2013). However, the paucity of research regarding how a history of cancer effects the perinatal period represents a significant void in understanding women's needs after cancer. Thus, the aim of the present study was to shed light upon women's experiences during this unique time in their lives in order to better understand women's health care and inform future care.

We found that women experience a duality of emotions during the perinatal period that is largely fueled by their history of cancer, encapsulated by the expression, I'm So Happy, but Also Terrified. While cancer may always colour other medical experience, women reflected that the perinatal period, particularly pregnancy, represented a comforting delineation between their cancer experience and their future, indicating that pregnancy may act as emotionally protective for women after cancer. Future studies are necessary to determine the protective impact of pregnancy on FCR and other forms of perinatal distress elicited by a history of cancer.

Women expressed frustration with the lack of information they received regarding fertility preservation before and during cancer treatments, as well as questions about maternal and fetal health during pregnancy. However, they indicated that they were better able to cope with the uncertainty of the effects of cancer on perinatal health when they had access to increased information regarding the risks of pregnancy, and when they felt supported by their healthcare team. Consistent with previous research, these results suggest that women require increased resources in order to better cope with the uncertainty of knowledge regarding fertility and perinatal health during and after cancer treatment (Andrykowski et al., 2008; Carneiro et al., 2018).

Limitations

The small sample size analyzed for the current study is a main limitation given that the experiences of women in this study may not be representative of a broader population. Additional research in this area would be helpful in order to demonstrate whether similar results extend to a broader population of perinatal cancer survivors. However, the fact that saturation was reached in the present analysis gives confidence that, for women of similar sociocultural background, comparable findings would be observed.

Another important limitation is the lack of diversity in our sample as all women were college educated, and the majority were Caucasian. Additionally, the majority of women had access to various health care services, including fertility and mental health services. Again, given the homogeneity of this sample, the results may not resonate with the broader population of perinatal women with a history of cancer. Increasing demographic variability in future studies may result in different findings, thus allowing for a more nuanced understanding of this phenomenon possibly leading to an improved standard of care for this population.

It is also important to note that a majority of research regarding FCR in female cancer survivors is specific to breast cancer and therefore, it is difficult to speculate whether results from the current analysis on the interrelationship between pregnancy and FCR in a mixed diagnosis sample of women supports extant literature. However, in the present sample there were few identifiable differences between women with breast cancer versus other disease types (e.g., non-Hodgkin's lymphoma, and leukemia). The only exception being specific worry regarding hormone receptor positive effects of fertility treatment for women diagnosed with estrogen- or progesterone-receptor positive breast cancer. Regardless, future research should aim to include a wider variety of disease type in order to ensure representativeness of women's experiences of the perinatal period.

Conclusions

To our knowledge, the present study was the first to examine the psychological effects of cancer on women's experiences of the perinatal period. Although the majority of results were consistent with existing literature, our analysis revealed several novel findings. Notably, the fact that, during pregnancy, changes in physical symptoms were not perceived as threatening when they were interpreted as being specific to pregnancy (e.g., morning sickness). This evaluation was made despite these symptoms being reminiscent of cancer treatment (e.g., chemotherapy induced nausea). Additionally, we found that, although women still had fears of recurrence throughout the perinatal period, pregnancy may also have acted as a buffer for increased distress.

Future studies could look at comorbidities for women who may be more prone to anxiety during the perinatal period and after a history of cancer. This may influence women's coping during pregnancy in relation to FCR. In general, the psychological effects of cancer during the perinatal period are not well understood and more research is needed in order to better support women during this vulnerable time. Consistent with existing, primarily quantitative literature, these qualitative findings suggest that women require additional information regarding fertility outcomes both during and after cancer treatment, as well as specialized healthcare provider support. Longitudinal research, capturing individual women's experiences throughout the perinatal period would also be useful in understanding whether certain timepoints are subject to increased distress and vulnerability (e.g., first trimester as most distressing for the majority of women given the increased rate of miscarriage after chemotherapy) – thereby justifying increased informational and emotional supports during this time.

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Appendix A

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 45 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. Do you have any questions for me before we begin?

So I would like to begin by asking you some questions about your history with cancer if that is ok? You mentioned in your survey that you had been treated for________________cancer back in [state month and/or year]

1. In hindsight, how do you feel you coped with the illness? What were some of the most challenging aspects for you? What did you find helpful?

2. Do you recall considering the possibility of pregnancy (or having more children if applicable) during your illness?

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

4. How has your experience of pregnancy been thus far? (if pregnant)

5. What was your most recent experience of pregnancy like? (if postpartum) (Inquire also re: breast feeding)

6. How have you been feeling physically over the course of your pregnancy (or since you gave birth)?

7. How have you been feeling emotionally over the course of your pregnancy (or since you gave birth) ? (Inquire also re: changes)

8. Were there any periods you found more difficult than any others?

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

10. How do you think your experience of cancer has affected your pregnancy (if at all)? (inquire on an emotional level and physical)

11. What was your experience of dealing with the health care system? What was the support like?

Appendix B

Hierarchical representation of emergent categories and their defining features