Using an Integrated Decision-Making Framework to Identify Factors Associated with Receipt of a Fertility Consultation by Canadian Female Cancer Patients

by

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Abstract

**Backgrounds:** Infertility is often a distressing consequence of cancer treatment for young women who have a desire for motherhood but have not yet completed their family at the time of cancer diagnosis. Guided by the Integrated Fertility Preservation Decision-Making Framework developed in my comprehensive paper, the overarching goal of this study is to identify the factors associated with young Canadian female cancer patients having a fertility discussion with their oncologists and receiving fertility preservation services prior to commencing cancer treatment.

**Methods:** A total of 188 young women who received a cancer diagnosis between the ages of 18 and 39 were recruited from cancer organizations, survivor networks, and digital media. Data were collected from September 2012 to June 2013 using an anonymous online survey.

**Results:** Although the survey participants were young women in their prime childbearing years when they received their cancer diagnosis, one quarter (n=45, 23.9%) did not recall having a fertility discussion with their oncologists. Of the three quarters who had a fertility discussion (n=143, 76.1%), discussions were equally initiated by oncologists (n=71) and patients (n=72). Of the 49 women (26%) who consulted a fertility specialist to discuss their cryopreservation options, 17 underwent a fertility preservation procedure to preserve unfertilized oocytes and/or embryos; this represents only 9% of the full sample. Cancer patients who had a high degree of fertility
concern at the time of cancer diagnosis had increased odds of receiving fertility services at all three decision points. The findings suggest that not only was the proactive behavior of oncologists in initiating a fertility discussion important, the qualities of the discussion were equally critical in supporting patients in their decision-making process.

**Conclusions:** Fertility preservation in oncology is an emerging area that requires partnerships involving health providers in the areas of both oncology and reproductive medicine. This study provides insight into the process that Canadian female cancer patients use to make their fertility preservation decisions in a stressful time-pressured situation. It also explores the validity of the newly developed decision-making framework and identifies significant factors associated with the receipt of fertility consultations.
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model who has taught me about using good social work research to influence clinical practice with an ultimate goal of building a more ethically accountable practice model.

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1.1 Background

The latest Canadian cancer statistics show that more than 93,000 women are diagnosed with cancer annually. Over 4,800 of these women are in their reproductive years between the ages of 20 and 39 (Canadian Cancer Society, 2014). Medical advances in cancer diagnostic screening and increasingly successful cancer treatments have led to a growing number of young women surviving cancer and living productive lives following cancer therapies. Fertility is an important quality of life issue for young women who have survived cancer (Crawshaw, Glaser, Hale, & Sloper, 2009; Reh, Lu, Weinerman, Grifo, Krey, & Noyes, 2011). Psychosocial studies have found that having a history of cancer does not necessarily diminish their desire to be parents. In fact, some cancer survivors found that their cancer experiences have enhanced their parenting skills and made them better parents (Dunn & Steginga, 2000; Schover, 1999, 2005).

Unfortunately, aggressive cancer treatment often compromises reproductive capacity in young female cancer patients. Some of the long-term side effects of cancer treatment on fertility include diminished ovarian reserve, premature menopause, and premature ovarian failure. Many young women may not be able to regain full reproductive capacity following their cancer treatment (Lee et al., 2006; Practice Committee of American Society for Reproductive Medicine [ASRM], 2013). Although current evidence suggests that pregnancy after cancer recovery does not increase a woman’s risk of recurrence, those who wish to become pregnant after cancer treatment are usually advised to wait approximately two years in case of cancer recurrence (Salani, Billingsley, & Crafton, 2014). Some cancer patients are put on hormonal treatments for at least five years following their chemotherapy and/or radiation therapy. During such time, pregnancy is not recommended due to adverse neonatal outcomes (Lambertini & Azim, 2014). Aside from cancer treatment, a woman’s reproductive window is restricted by their biological clock and age. By the time the cancer survivors are ready to attempt pregnancy, there will be a natural decline in their fertility due to diminished egg quantity and quality (Practice Committee of ASRM, 2013; Society for Assisted Reproductive Technology & Practice Committees of ASRM, 2013).
For young women who have a desire for motherhood but have not yet completed their family at the time of cancer diagnosis, infertility could be a distressing consequence of cancer treatments (Duffy, Allen, & Clark, 2005; Halliday & Boughton, 2010). Three systematic reviews concluded that young women who have subsequently developed infertility issues following their cancer treatment have more psychosocial distress and less life satisfaction than other women who are able to conceive post cancer treatment (Peate, Meiser, Hickey, & Friedlander, 2009; Sobota & Ozakinci, 2014; Tschudin & Bitzer, 2009).

In the past, young female cancer patients had limited chances to preserve their fertility at the time of receiving a diagnosis. Improved ovarian stimulation protocols and advances in cryopreservation techniques in the past decade have made it feasible for more young women to preserve eggs and embryos prior to commencing cancer treatment, thereby enhancing the likelihood they may have children in the future (Ethics Committee of ASRM, 2013). Most established cryopreservation procedures involve the use of in-vitro fertilization procedure, which must synchronize with the woman’s menstrual cycle (Kim, Klemp, & Fabian, 2011). The process of harvesting oocytes using fertility medications takes approximately two weeks from the onset of menstruation to stimulate follicle development in the ovaries. Embryo cryopreservation requires the use of sperm to fertilize egg. Women who do not have male partners must consider the use of anonymous sperm donation from a sperm bank, which can complicate further an already difficult decision (Klock, Zhang & Kazer, 2010). Oocyte freezing does not require the use of sperm to create embryos and is a cryopreservation option for women (Society for Assisted Reproductive Technology & Practice Committees of ASRM, 2013). However, the efficacy of fertility preservation procedure is restricted by the female’s age. In general, fertility preservation for advanced aged cancer patients beyond 40 years is not recommended because the chance of harvesting enough oocytes for cryopreservation to have a successful live birth in the future is low (Marcelo, Cruz, Prestes, Gimenes, & Fanelli, 2010; Stoop, Cobo, & Silber, 2014).

Medical societies in Australia (Clinical Oncological Society of Australia [COSA], 2011), Canada (Canadian Fertility and Andrology Society [CFAS], 2014), the Netherlands (Louwé et al., 2013), the UK (National Institute for Health and Care Excellence [NICE], 2014) and the US (Lee et
(Loren et al., 2013; Practice Committee of ASRM, 2013) have issued clinical practice guidelines which emphasize the important role of oncologists in ensuring routine communication with young cancer patients about the potential fertility risks associated with cancer treatment. Not only should cancer patients be informed about their options to preserve fertility prior to commencing cancer treatment, expeditious referrals to fertility centers should be made if they want to pursue these options in order to avoid causing a significant delay in cancer treatment. These guidelines also highlight the clinical roles not just for oncologists, but also for clinicians and practitioners who work with cancer patients in inter-professional practice settings (Practice Committee of ASRM 2013; Lee et al., 2006; McConnell, Stankiewicz, & Koczwara, 2011; Woodruff, 2008; Woodruff, Clayman & Waimey, 2014).

Fertility preservation in oncology is an emerging area that is very relevant to social workers who practice in multi-disciplinary oncology centres, as well as in individual and family services related to direct practice, family planning, and reproductive health (Gardino et al., 2010; Kelvin & Reinecke, 2012). Fertility preservation in oncology is an emerging area that requires partnerships involving health providers in the areas of both oncology and reproductive medicine (Woodruff, 2010; Zebrack & Walsh-Burke, 2004). In oncology practice settings, social workers can act as fertility preservation navigators or liaisons in clinical care in order to follow through with the care plan initiated by oncologists (Elizur et al., 2009; King et al., 2008). Their roles could include that of providing psychosocial care to patients and their partners who have fertility concerns, making expeditious referrals to fertility preservation programs which have experience in dealing with cancer patients, and being the liaison between the oncology and fertility preservation teams for greater integration of care across these health care settings. Social work can also be a catalyst in promoting seamless access to services through collaboration, advocacy, resources building, and program planning in assisting young cancer patients to access timely fertility interventions (Gambrill et al., 2005; Ronn and Holzer et al., 2013b; Treves et al., 2011).
1.2 Statement of problems

1.2.1 Lack of information from oncologists about treatment-induced fertility risks

Despite the recommendations by oncology medical societies to standardize fertility preservation practice in cancer care, extant data suggest that fertility information is far from being offered universally. Previous studies have found that oncologists do not always inform young cancer patients about the potential fertility risks when making plans for cancer treatment (Forman, Anders, & Behera, 2010; Quinn et al., 2009a, 2009b; Yee, Fuller-Thomson, Lau, & Greenblatt, 2012d). Barriers related to physician characteristics (Forman et al., 2010; Quinn, Vadaparampil, Bell-Ellison, Gwede, & Albrecht, 2008), patient factors (Geue et al., 2014; Sobota & Ozakinci, 2014), logistic constraints (Quinn et al., 2008; Quinn & Vadaparampil, 2009), and practice cultures (Ghorbani, Madahi, Shirazi, Ardekani, & Kamali, 2011; Quinn et al., 2012; Yee, et al. 2012d) appear to impede oncologist capacities in discussing fertility matters with cancer patients. Quantitative studies conducted in Australia (Thewes et al., 2005), France (Mancini, Rey, Preau, Malavolti, & Moatti, 2008), and the U.S. (Duffy et al., 2005; Partridge et al., 2004) using datasets ranging from 116 to 1702 female cancer survivors found that many of them did not have a discussion with their oncologists on the potential negative side effects of cancer treatment on their fertility (Duffy et al., 2005; Mancini et al., 2008; Schover, Rybicki, Martin, & Bringelsen, 1999). Qualitative research literature has also drawn similar conclusions. Most did not recall being alerted by or having a fertility discussion with their oncologists about the potential treatment-induced fertility risks (Connell, Patterson & Newman, 2006; Dunn & Stegina, 2000; Reis, Beji, & Coskun, 2010).

Oncologists play a pivotal role in the provision of fertility information to cancer patients at the time of diagnosis (Quinn et al., 2007; Yee et al., 2012d). To date, little is known about how the fertility concerns of young Canadian female patients were addressed by their oncologists and if they were satisfied with the quality of their fertility discussion. The systemic barriers encountered by cancer patients in accessing fertility services and resources at the time of cancer diagnosis are not well understood (Goossens, Delbaere, Van Lancker, Beeckman, Verhaeghe, & Van Hecke, 2014).
1.2.2 Lack of fertility preservation consultation with fertility experts

Oncologists are gate-keepers for cancer patients to receive fertility preservation services. They play a crucial role in making timely referrals for concerned cancer patients to see a fertility specialist to discuss cryopreservation options (Ronn & Holzer, 2013). Prior research has shown that many young women have a strong interest in receiving fertility preservation services after having a fertility discussion with their oncologists (Gorman, Bailey, Pierce, & Su, 2012; Peate, et al., 2009); most have favorable attitudes towards undergoing procedures to preserve fertility if given an opportunity (Garavelink, 2013; Tschudin, Bunting, Abraham, Gallop-Evans, Fiander & Boivin, 2010). Studies found that speaking to a fertility specialist on the efficacy, benefits, risks, success rates, and costs associated with fertility preservation procedures is the optimal way of obtaining personalized fertility preservation information (Peate et al., 2009; Thewes et al., 2005). This information is essential in order for cancer patients to make an informed medical decision.

Unfortunately, fertility preservation is an area that does not seem to receive much attention among Canadian oncology health providers (Ronn & Holzer, 2013; Yee et al., 2012b; Yee et al., 2013). Denying young cancer patients the choice for informed fertility preservation decision by not referring them to see a fertility specialist in a timely manner may lead to patient regret and undermines their reproductive autonomy (Connell, Patterson, & Newman, 2006; R.J. Lee et al., 2011). There is an urgent need to understand the challenges and barriers encountered by young cancer patients in accessing timely fertility preservation services in Canada during cancer care.

1.2.3 Difficult fertility preservation decision under stress and time pressure

Cancer patients have to make a decision regarding their plan to pursue fertility preservation soon after consulting a fertility specialist. Dealing with a life threatening cancer diagnosis as well as the possibility that cancer treatment may have negative implications on future fertility creates a very complex scenario in treatment decision-making for these young women. The window of preserving fertility using established fertility preservation procedures is short and time sensitive (Klock et al., 2010; Lee, Ozkavukcu, Heytens, Moy, & Oktay, 2010). The decision to proceed with fertility preservation usually has to be made shortly after a single consultation with a fertility specialist in order to allow time for completing the medical procedure before starting cancer
treatment (Bastings et al., 2014; Mersereau et al., 2013). Unlike infertile individuals/couples who have the time to do research and to explore all available assisted reproductive treatment options, cancer patients do not usually have such luxury to thoroughly research and process the information upon which their decision will be based (Balthazar, Fritz & Mersereau, 2011; Hill et al., 2012). This timeframe in decision-making coincides with an enormous amount of stress and time pressure due to the urgency of initiating cancer treatment (Hershberger, Finnegan, Altfeld, Lake, & Hirshfeld-Cytron, 2013).

To date, limited data are available to understand the complex decision-making processes in fertility preservation confronting young women who are newly diagnosed with cancer (Peddie et al., 2012; Peate et al., 2012; Garvelink et al., 2013). Available Canadian data on the psychosocial aspects of fertility preservation in young female cancer patients were primarily reported from studies with participants recruited from fertility programs affiliated with academic institutions, and these patients had already been referred by their oncologists to receive fertility preservation services (Hill et al., 2012; Yee et al., 2012a). To date, no community data are available regarding the prevalence of the receipt of fertility services in young female cancer patients at the time of their cancer diagnosis. Besides, how young female cancer patients weigh and balance this treatment decision while dealing with a life-threatening illness, and the factors associated with their decision of whether to proceed or not with fertility preservation are not well understood. Furthermore, Canada has a publicly funded cancer care model delivered by provincial and territory health systems. The federal government has mandates in cancer prevention and control to maintain the health of Canadians (Sutcliffe, 2011). As most of the available psychosocial data in fertility preservation are from studies conducted in other countries with different health delivery care models, extrapolation of research data to the Canadian setting could be problematic due to differences in health care philosophies.
1.3 Theoretical foundations

1.3.1 Theoretical underpinnings of “managing stress”

Stress plays an integral role in impacting an individual's appraisal skills, affecting their decision-making and coping capacity. Lazarus and Folkman's Transaction Model of Stress and Coping Theory (Lazarus & Folkman, 1987, 1994) is the most commonly used model to conceptualize the theories of stress and coping. In this model, stress is defined as a contextual relationship involving the interaction of, and transaction between, two systems – the person and the environment. Stress is generated when the situation is significant to an individual, the demands exceed an individual’s capacity to cope, and the available resources exceed an individual's ability to manage the situation.

The appraisal process is based on the assumption that people constantly appraise their ‘self’ in a particular situation in relation to their environment (Park & Folkman, 1997). One may ask for example, ‘What does being infertile post cancer treatment mean to me?’ The two levels of stress appraisal are: a) Primary appraisal -- an appraisal of the personal significance of a specific event and its person-environment transaction (e.g. ‘what is the side effect of cancer treatment on my fertility?’; ‘am I at risk of developing infertility issues after finishing my cancer treatment?’; ‘if I am not able to have children, how would it affect my life?’), and b) Secondary appraisal -- an evaluation of the options and resources available to allay the person-environment problem. This includes an assessment of possible coping strategies and the adequacy of the individual’s physical, psychological, and emotional resources for coping (e.g. ‘do I have any options to protect my fertility?’; ‘do I have time and resources to pursue these options prior to my cancer treatment?’). Negative emotions – such as fear, anger, anxiety, and depression – are generated when the situation is appraised as a fertility threat with serious personal consequences such as involuntary childlessness (Folkman, 2010; Folkman & Geer, 2000).

1.3.2 Theoretical underpinnings of “embracing uncertainty”

For events that are characterized by inconsistency, complexity, unpredictability, and ambiguity, stress is generated when dealing with the uncertainty of when something will happen (Temporal uncertainty), what will happen (Event uncertainty), what can be done when something
happens (*Efficacy uncertainty*), and what the outcome will be when something is done (*Outcome uncertainty*) (Folkman, 2010; Mishel, 1998; Penrod, 2001). Using Mishel’s Theory of Uncertainty in Illness Model (Mishel, 1990), it is hypothesized that uncertainty arises when the potential fertility risks caused by cancer treatment are unfamiliar or when oncologists are ineffective in communicating the fertility risks to cancer patients. Uncertainty may occur when cancer patients are unable to receive adequate fertility information to understand their risks or are unable to obtain a timely fertility preservation consultation to discuss their options (Duffy et al., 2005; Thewes, Meiser, Rickard, & Friedlander, 2003).

In the context of fertility preservation for cancer patients, a woman may lack the knowledge of her fertility risks and fertility preservation options if her oncologists do not initiate a fertility discussion with her during the cancer care. She may not have an opportunity to see a fertility specialist if fertility preservation options are never mentioned or recommended. Furthermore, negative emotions may arise if her oncologist is insensitive to her desire for childbearing and dismisses her fertility concerns when planning for cancer treatment, or if the fertility discussion is ambiguous or not well organized. As a result, she is more likely to appraise the event as a threat, harm, or loss when the level of uncertainty is high. On the other hand, a woman is more likely to appraise the opportunity to preserve fertility as hopeful if the fertility risk is well explained by her oncologists, if she has a chance to meet with a fertility specialist to discuss her options to preserve fertility, and if she has the support from her oncologists to make an informed medical decision regarding the uptake of fertility preservation.

### 1.3.3 Theoretical underpinnings of “maintaining hope”

The Hope Theory (Snyder, 2002; Snyder et al., 2002) is a strength-based positive psychology model where human behaviours are viewed as primarily goal-driven and purposeful. Hope is characterized by the belief that it is possible to achieve something in the future, that the present situation can be modified, and that there is a way out of current difficulties. Hope is motivational because hopefulness generates positive emotional energy to protect one’s psychological well-being so that an individual can continue to push forward despite encountering setbacks. The calming effects of hope in managing anxiety can enhance one’s overall capacity to deal with
stressful situations (Hammer, Mogensen, & Hall, 2009; Ong, Edwards & Bergeman, 2006). Underpinning the Hope Theory are two goal-directed interrelated cognitive components: agency thinking (goal-directed determination) and pathway thinking (ways to meet goals) (Snyder, 2002; Snyder, Rand, & Sigmon, 2002). *Agency thinking* refers to the individual’s perception of their ability to initiate and maintain the actions needed to meet their goals, as well as confidence in their ability to overcome a particular circumstance. *Pathway thinking* refers to the individual’s belief in their capacity to generate strategies to attain their desired goals. Agency thinking and pathway thinking jointly determine how and when people attempt to pursue or disengage from goal pursuits (Horton & Wallander, 2001; Ong, Edwards, Bergeman, 2006).

The treatment decision-making styles of individuals are theorized to be influenced by their agency thinking and pathway thinking patterns based on the Hope Theory. Consider three young women with cancer in the context of considering fertility preservation. The first woman was not informed by her oncologist about available options to protect her fertility (i.e. no pathways of thinking), therefore her motivation (i.e. agency thinking) cannot be applied. The second woman believes that fertility preservation is effective and that she can navigate through the system with the help of her oncologist (i.e. high pathway thinking), so her motivation (i.e. high agency thinking) can be applied to pursue fertility preservation. The third woman knows about the fertility preservation options (i.e. high pathways of thinking), but lacks the motivation to follow through (i.e. low agency thinking). Despite her good pathway thinking, her low agency leaves her immobilized to pursue fertility preservation.

### 1.3.4 Theoretical underpinnings of health belief

The treatment decision-making styles of individuals could also be influenced by their health belief systems. According to the Health Belief Model (Rosenstock, 1974, 1990), the likelihood of an individual willing to take action to prevent a health risk depends upon four factors: (a) *perceived severity of a health risk* (e.g. if the fertility risk is high and the consequences of being infertile are serious to the individual); (b) *perceived personal susceptibility and vulnerability to the disease* (e.g. if the individual has a high chance of being infertile following cancer treatment); (c) *perceived benefits of and barriers to taking the recommended action* (e.g. if fertility preservation is perceived
to be an effective treatment option to protect future reproductive chances or if there are impediments to undertaking the recommended fertility preservation option); (d) a stimulus, such as a cue to action from oncologists, is necessary to trigger the decision-making process.

1.3.5 Integrated decision-making framework

The theoretical constructs of stress, uncertainty, and hope are appraisal- and context-based, dynamic, and reciprocal in nature, involving the interaction of, and transaction between, the person and the situation (Folkman, 2010; Hammer, Mogensen, & Hall, 2009; Park & Folkman, 1997). Certainty intertwines with uncertainty, just as hope intertwines with hopelessness. Hope plays an important role in moderating stressful life events, minimizing uncertainty, and mediating stress recovery (Folkman, 2010; Snyder, 2002). Hope sustains coping, and coping in turn fosters hope and reduces stress. Facing a life threatening illness is no doubt a very stressful life event, creating high levels of anxiety and uncertainty. Upon receiving a diagnosis, cancer patients have to deal with complex medical information and make treatment decisions within a relatively short timeframe.

The Integrated Fertility Preservation Decision-Making Framework (Figure 1) is a new synthesized framework developed in my comprehensive paper (Yee, 2011) to conceptualize how cancer patients manage stress, embrace uncertainty, and maintain hope while making a difficult decision regarding fertility preservation under the non-ideal circumstance of having cancer (Halliday & Boughton, 2010; Hershberger et al., 2013). This new framework synthesizes the theories drawn from the Transaction Model of Stress and Coping Theory (Lazarus & Folkman, 1987, 1994), Theory of Uncertainty in Illness Model (Mishel, 1990), Hope Theory (Snyder, 2002; Snyder et al., 2002), and Health Belief Model (Rosenstock, 1974, 1990).

In this framework, decision-making is theorized to be a highly individualized process influenced by the decision maker’s socio-demographic history, personal characteristics, cancer history, and treatment decision-making style [Stage 1]. The decision to proceed or not with fertility preservation begins with an awareness of the potential treatment-induced fertility risks through information provided by knowledge brokers (i.e. oncologists and oncology health providers such
as nurses and social workers) and credible sources (i.e. educational materials published by authoritative medical societies and national cancer organizations) [Stage 2], followed by in-person fertility risk appraisal based on her personal circumstances [Stage 3]. The decision maker has to appraise the severity of the potential fertility threat in her personal context, and her available fertility preservation options based on the personalized medical information obtained from her oncologists and the fertility specialist [Stage 4]. In the final stage, the decision maker has to decide on what she wants to do with the fertility threat and if fertility preservation is a feasible option given her personal and medical circumstances such as the urgency of starting cancer treatment. A cue to action from her oncologists to pursue fertility preservation is crucial in decision-making [Stage 5].

**Stage 1: Antecedents**

Antecedents refer to the decision maker’s socio-demographic history, personal characteristics, cancer history, and treatment decision-making style (e.g. passive, collaborative, or active). Each individual is different in her preferred medical decision-making style based on her agency thinking and pathway thinking patterns. Some cancer patients may take on a more active role in driving the fertility discussion with their oncologists; others who are overwhelmed by their cancer diagnosis may want to passively rely on their oncologists for information provision and treatment recommendation (Cameron, 2009; Power, Swartzman, & Robinson, 2011).

**Stage 2: Fertility risk awareness**

The two types of information providers in this Integrated Fertility Preservation Decision Making Framework are a) Reliable educational materials provided by authoritative medical societies and national cancer organizations to facilitate oncologist-patient fertility discussions (Kahlor & Mackert, 2009) and b) Personalized medical information provided by oncologists and oncology health providers (Quinn et al., 2007). Discussion of the potential fertility threat due to cancer treatment is a sensitive topic, particularly when the participating young women have just received a devastating diagnosis of cancer. Oncologists undoubtedly play a crucial role as knowledge brokers to deliver this personalized message (Wallace, 2007; Zebrack, 2008).
Receptivity is high if the message is communicated with sensitivity, openness, and sincerity (Cameron, 2009).

**Stage 3: In-person fertility risk appraisal**

The fertility risk appraisal is subjective and personal because it is highly context-specific; when a situation changes, so does the relationships between the person and situation (Park & Folkman, 1997). On the *primary risk appraisal* level, a young woman will evaluate if the potential fertility risk is personally significant and relevant (e.g. ‘Do I want to have children after finishing cancer treatment?’; ‘if the fertility risk is real, would I be able to live a life without having children?’). On the *secondary risk appraisal* level, she will evaluate if the available options meet her needs (e.g. ‘Can I afford the time to see a fertility specialist without causing a life-threatening delay in my cancer treatment?’). When uncertainty is appraised as a threat or harm, problem- and emotional-focused coping strategies are frequently used. Under this situation, the decision maker will actively try to cope with the situation using a range of cognitive, emotional, and behavioural strategies (Mishel, 1998; Power et al., 2011).

**Stage 4: Fertility preservation awareness**

As each cancer patient presents a unique clinical picture, a fertility preservation option that is applicable to one patient may not be medically suitable to another. Meeting with a fertility specialist to discuss personalized fertility preservation options can motivate a cancer patient to derive strategies to protect her fertility. The availability of options and professional support will then increase her self-agency in managing the fertility threat.

**Stage 5: Fertility preservation decision-making**

Being aware of one’s susceptibility to the severity of fertility risks can facilitate the utilization of appropriate coping responses to deal with the potential fertility threat associated with cancer treatment. In this final stage, the decision-maker engages in a cost-benefit analysis of the potential risks and benefits associated with each recommended option. For example, a woman is more likely to preserve fertility if a) she perceives the fertility message as personally relevant, b) she places a high value on motherhood and she has not yet completed her family, c) she perceives
the severity of developing infertility following cancer treatment to be serious with high personal consequences, d) the likelihood for her to be infertile post-cancer treatment is high, e) fertility preservation is an effective way to preserve her future motherhood chance, f) the benefits of proceeding with fertility preservation are high and the perceived barriers are manageable, and g) fertility preservation is recommended and supported by her oncologists.

1.4 Research Questions

Often, the decision of whether to preserve fertility for cancer patients has to be made under less than ideal circumstances that are characterized by high levels of stress, time pressure, uncertainty, and psychological vulnerability. For many cancer patients, the narrow window of time for decision-making usually coincides with the emotional stress of receiving a cancer diagnosis, dealing with the uncertainty of the cancer prognosis, and making cancer treatment plans (Degner et al., 1997; Peate et al., 2011). Since fertility preservation is a time-sensitive medical procedure, the time pressure in decision-making is even more acute for cancer patients in order to avoid life-threatening delays in initiating cancer treatment.

The proposed Integrated Fertility Preservation Decision-Making Framework in Figure 1 aims to conceptualize the processes in which young cancer patients seek fertility information, discuss fertility concerns with oncology health providers, appraise the severity of the fertility threats, engage in risk-benefit analysis of the available fertility preservation options, and finally make a fertility preservation decision prior to commencing cancer treatment. The analysis was situated in a bio-psychosocial framework to examine the existing gaps within the cancer care system of Canada with regards to the provision of fertility services to young women newly diagnosed with cancer (Crawshaw, 2013b; Hershberger, Finnegan, Altfeld, Lake, & Hirshfeld-Cytron, 2013). The potential contribution that social work can make in research, clinical practice, advocacy, resource development, and program development within a multi-disciplinary and inter-professional practice models are explored (King et al., 2008; Treves et al., 2011).
Figure 1: An Integrated Fertility Preservation Decision-Making Framework

STAGE 1: Antecedents

- Socio-demographic characteristics
- Cancer profile
- Treatment decision making styles

STAGE 2: Fertility Risk Awareness

- Personalized medical information
  - Medical consultation with oncologists
  - Reliable patient educational resources
  - Information published by credible cancer organizations

STAGE 3: In-Person Fertility Risk Appraisal

- Awareness of cancer treatment-induced fertility risks
  - Had a fertility discussion
  - No discussion

STAGE 4: Fertility Preservation Awareness

- Self-in-situation fertility risk appraisal
  - Primary appraisal
  - Secondary appraisal
  - No referral
  - Had a referral

STAGE 5: Fertility Preservation Decision-Making

- Fertility preservation option appraisal
  - Seeing a fertility specialist for consultation
  - Fertility preservation attitudes and knowledge

- Informed fertility preservation decision
  - Proceed
  - Not to proceed

1. Perceived severity
2. Perceived personal susceptibility
3. Perceived benefits
4. Perceived barriers
5. Cue for action from oncologists
The overarching goal of this study is to identify the factors associated with young Canadian female cancer patients having a fertility discussion with their oncologists, and with receiving fertility preservation services provided by a fertility specialist prior to commencing their cancer treatment. These include having a fertility discussion with their oncologists about the potential fertility risks associated with their cancer treatment [Stage 2], having a fertility preservation discussion with a fertility specialist about their options [Stage 3], and making a decision about whether to preserve fertility prior to commencing cancer treatment [Stage 4 and Stage 5]. In addition, it seeks to understand what types of challenges and barriers exist in the broader socio-medical context that may influence the equity of access to these essential fertility services.

The first research question of this study investigates the factors associated with young cancer patients having a fertility discussion with their oncologists at the time of cancer diagnosis, and if their fertility concerns were addressed appropriately, sensitively, and effectively by their oncologists. To the best of my knowledge, this is the first study examining the factors associated with Canadian female cancer patients having a fertility discussion that was initiated by oncologists rather than patient prompting.

The second research question examines the factors associated with young cancer patients consulting with a fertility specialist after having a fertility discussion with their oncologists. Specifically, the importance of the quality of fertility discussion cancer patients had with their oncologists prior to being referred to see a fertility specialist is investigated. The trends and disparities for cancer patients in accessing timely fertility preservation services related to their personal characteristics, socio-demographics, and cancer history are examined.

The third research question examines the factors associated with female cancer patients’ decisions to preserve their fertility after having consulted with a fertility specialist. The role of oncologists in helping cancer patients make a high quality fertility preservation decision under time pressure is examined. Although making a decision regarding fertility preservation while dealing with a life threatening cancer diagnosis is inherently stressful for cancer patients, it is hypothesized
that those who were satisfied with their fertility discussion with their oncologists and those who find their oncologists supportive of their fertility preservation decision are more satisfied with the quality of their decision and have less post-decision regret. To the best of my knowledge, this is the first study examining the association between fertility discussions provided by oncologists with the uptake of fertility preservation procedure.

1.5 Research Methodology

1.5.1 Inclusion and exclusion criteria

The study was approved by the University of Toronto’s Health Sciences Research Ethics Board in August 2012 (Appendix A). Annual ethics review approvals to extend the study period were obtained in August 2013 (Appendix B) and August 2014 (Appendix C). Subjects were recruited through cancer organizations and survivor networks using a non-probability community-based convenience sampling. Participants were female cancer survivors who received a cancer diagnosis in Canada since January 2000, and at the time of diagnosis these women were between the ages of 18 and 39. They had completed active cancer treatment such as chemotherapy, stem cell transplantation, and radiation by the time of the survey. The upper age limit of 39 was chosen because fertility preservation for advanced age women have suboptimal medical outcomes due to age-related fertility decline and poor egg quality.

1.5.2 Survey construction

A questionnaire with 115 items grouped under ten substantial sections was developed for the purpose of this study (see Appendix D). These include: a) current demographics and health status (12 questions), b) cancer history and demographics when diagnosed with cancer (9 questions), c) motherhood status and desire for parenthood (11 questions), d) fertility issues related to cancer care (16 questions), e) information seeking of fertility resources (9 questions), f) referral for fertility consultation (11 questions), g) decision-making about fertility preservation (20 questions), h) knowledge of cancer-related fertility matters and assisted reproductive services (10 questions), i) coping and stress management (15 questions), and j) miscellaneous (2 questions).
Among the 115 items in the questionnaire, 31 items were borrowed from five standardized scales with established psychometric properties: 1) *Control Preference Scale* (Degner, Sloan, & Venkatesh, 1997), 2) *Informed Choice Subscale from the Treatment Decision Evaluation Scale* (Stalmeier et al., 2005), 3) *Satisfaction with Decision Scale* (Holmes-Rovner, 1996), 4) *Decision Regret Scale* (Brehaut et al., 2003), and 5) *Ways of Coping Checklist – Revision* (Cousson-Gelie et al., 2010). In the latter, only the Problem-Focused Coping subscale and the Self-Blamed Attribution and Avoidance sub-scale were used. Sixty-one questions in the questionnaire were mandatory and the remaining 54 questions were optional. Participants only had to answer the questions that were relevant to their personal circumstances. For example, Sections F & G would not appear on the online questionnaire for participants who did not consult with a fertility specialist.

An online survey tool, FluidSurveys (http://fluidsurveys.com/), was used to develop the questionnaire. This software tool has built-in looping, skipping, and branching functions for conditional questions. The cover page of the online questionnaire also served as the consent form to participate in the study (Appendix E). Participants could not start the survey unless they selected ‘Yes’ in the checkbox of the consent form (see Appendix F of print screen). Nine young female cancer survivors recruited from two cancer organizations\(^1\) pilot-tested the online survey for content validity and readability. Minor revisions were made based on their feedback with regards to formatting, structure, clarity, and inclusiveness of options in multiple choice questions. Four of them completed the revised survey two weeks afterward.

### 1.5.3 Data collection

A project website was developed to provide background information about this study and to host the web-based questionnaire (Appendix G). Designated Facebook (‘Cancer, Fertility, and Motherhood’) and Twitter (@CancerFertility) accounts were created as well for data collection purpose (see Appendix H of print screens). Survey participants were recruited from cancer centres, cancer organizations, and cancer survivor networks using a non-probability convenience

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\(^1\) Young Adult Cancer Canada [http://www.youngadultcancer.ca](http://www.youngadultcancer.ca), and Rethink Breast Cancer [http://rethinkbreastcancer.com/](http://rethinkbreastcancer.com/)
community sampling. An Internet search was conducted to generate a participant list of cancer organizations and groups across Canada, of which approximately 100 were identified. After obtaining ethics review approval from the University of Toronto, an invitation email was sent to all the cancer groups on the participant list to request their help in disseminating the recruitment notices through their cancer networks. A second email to non-responding agencies was sent two weeks later, followed by another email after a further three weeks.

A total of 53 cancer groups (Appendix I) helped promote the study by disseminating the recruitment notice, as well as posting the study’s website domain and survey’s hyperlink through their channels, e.g. newsletters, email distribution lists, blogs, bulletin board posting, Facebook, and Twitter (see Appendix J of print screens). In addition, permissions were obtained from the hospitals’ research ethics boards of University Health Network, Sunnybrook Health Centre, and Women’s College Hospital to post the recruitment notices at the Patients’ Resource Centre and information bulletin boards at the hospitals. Advertising websites (i.e. Kijiji, Craigslist), Facebook (‘Cancer, Fertility, and Motherhood’), and Twitter (@CancerFertility) were used to reach out to potential participants through digital media (see Appendix K of recruitment flyers). Participants were not directly rewarded for survey completion but were offered a monthly draw to win one of the five $20 gift cards.

1.5.4 Data analysis

During the 10-month data collection period from September 2012 to June 2013, approximately 250 women accessed the online survey. A total of 188 completed surveys were used for analyses. Many participants wrote descriptive comments in the open-ended questions. The materials provided nuanced information to enhance our understanding of patients’ experiences of fertility discussion with their oncologists, and their perspectives about seeing a fertility specialist to discuss their fertility preservation options at the time of cancer diagnosis. Written comments were first grouped under each individual open-ended question. Thematic analysis using topics informed by the psycho-social literature on fertility preservation was to gain a more detailed understanding of participants’ experiences (Boyatzis et al., 1998; Strauss & Corbin, 1998). Extracts
from the qualitative comments, where applicable, were cited in quotation to illustrate participants’ views in their own words.

Data analyses were conducted using the Statistical Package for the Social Sciences (SPSS) version 22.0. The sample composition of the receipt of fertility services is shown in Figure 2. Among the 188 survey participants, a quarter (n=45, 23.9%) indicated that they did not have any fertility discussion with their oncologist at the time of their cancer diagnosis. Of the three quarters (n=143, 76.1%) who were informed by their oncologists about the fertility risks associated with their cancer treatment, 51 (27%) were subsequently referred to see a fertility specialist for a fertility preservation consultation. Of the 49 women (26%) who saw a fertility specialist, 17 (9%) proceeded with cryopreservation of oocytes and/or embryos prior to commencing cancer treatment.

Figure 2: Sample composition of the receipt of fertility services (n=188)

Descriptive statistics were used to tabulate the socio-demographic characteristics and cancer profiles of 188 participants by the receipt of fertility services. The participants’ socio-demographic characteristics at the time of survey completion are shown in Table 1 and at their cancer diagnosis are shown in Table 2. Their cancer profiles are shown in Table 3.
Table 1: Socio-demographic characteristics of 188 participants at survey completion

<table>
<thead>
<tr>
<th>Current age</th>
<th>All n=188 (%)</th>
<th>No discussion n=45 (%)</th>
<th>Had a fertility discussion with oncologists n=143 (%)</th>
<th>Did not consult a fertility specialist following a discussion n=94 (%)</th>
<th>Consulted a fertility specialist following a discussion n=49 (%)</th>
<th>Proceeded with fertility preservation n=17 (%)</th>
</tr>
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<td>Between 18 and 24</td>
<td>13 (6.9%)</td>
<td>3 (6.7%)</td>
<td>10 (7%)</td>
<td>10 (10.6%)</td>
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<td>Between 25 and 29</td>
<td>27 (14.4%)</td>
<td>6 (13.3%)</td>
<td>21 (14.7%)</td>
<td>15 (16%)</td>
<td>6 (12.2%)</td>
<td>4 (23.5%)</td>
</tr>
<tr>
<td>Between 30 and 34</td>
<td>59 (31.4%)</td>
<td>12 (26.7%)</td>
<td>47 (32.9%)</td>
<td>21 (22.3%)</td>
<td>26 (53.1%)</td>
<td>7 (41.2%)</td>
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<tr>
<td>Between 35 and 39</td>
<td>54 (28.7%)</td>
<td>11 (24.4%)</td>
<td>43 (30.1%)</td>
<td>29 (30.9%)</td>
<td>14 (28.6%)</td>
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</tr>
<tr>
<td>Between 40 and 44</td>
<td>29 (15.4%)</td>
<td>11 (24.4%)</td>
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<td>16 (17%)</td>
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<td>1 (5.9%)</td>
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<td>Above 45</td>
<td>6 (3.2%)</td>
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<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
<td>94 (100%)</td>
<td>49 (100%)</td>
<td>17 (100%)</td>
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<td>Heterosexual</td>
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<td>43 (95.6%)</td>
<td>140 (97.9%)</td>
<td>92 (97.9%)</td>
<td>48 (98%)</td>
<td>16 (94.1%)</td>
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<td>Same-sex</td>
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<td>Others</td>
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<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
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<td>White</td>
<td>163 (86.7%)</td>
<td>38 (84.4%)</td>
<td>125 (87.4%)</td>
<td>81 (86.2%)</td>
<td>44 (89.8%)</td>
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<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
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<td>No</td>
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<td>42 (93.3%)</td>
<td>129 (90.2%)</td>
<td>82 (87.2%)</td>
<td>47 (95.9%)</td>
<td>30 (93.8%)</td>
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<td>17 (9%)</td>
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<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
<td>94 (100%)</td>
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<td>College or technical school</td>
<td>51 (27.1%)</td>
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<td>64 (44.8%)</td>
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<td>Graduate</td>
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<tr>
<td>Total</td>
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<td>45 (100%)</td>
<td>143 (100%)</td>
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<td>Yes</td>
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<td>143 (100%)</td>
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<td>Single, never married</td>
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<td>13 (28.9%)</td>
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<td>23 (24.5%)</td>
<td>10 (20.4%)</td>
<td>4 (23.5%)</td>
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<tr>
<td>Married or partnered</td>
<td>130 (69.1%)</td>
<td>27 (60%)</td>
<td>103 (72%)</td>
<td>66 (70.2%)</td>
<td>37 (75.5%)</td>
<td>13 (76.5%)</td>
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<tr>
<td>Separated or divorced</td>
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<td>5 (11.1%)</td>
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<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
<td>94 (100%)</td>
<td>49 (100%)</td>
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<p>| Changes of relationship status since diagnosis | |
|-----------------------------------------------| |</p>
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<tr>
<th></th>
<th>All n=188 (%)</th>
<th>No discussion n=45 (%)</th>
<th>Had a fertility discussion with oncologists n=143 (%)</th>
<th>Did not consult a fertility specialist following a discussion n=94 (%)</th>
<th>Consulted a fertility specialist following a discussion n=49 (%)</th>
<th>Proceeded with fertility preservation n=17 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age at diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between 18 and 24</td>
<td>35 (18.6%)</td>
<td>7 (15.6%)</td>
<td>28 (19.6%)</td>
<td>24 (25.5%)</td>
<td>4 (8.2%)</td>
<td>2 (11.8%)</td>
</tr>
<tr>
<td>Between 25 and 29</td>
<td>43 (22.9%)</td>
<td>6 (13.3%)</td>
<td>37 (25.9%)</td>
<td>19 (20.2%)</td>
<td>18 (36.7%)</td>
<td>5 (29.4%)</td>
</tr>
<tr>
<td>Between 30 and 34</td>
<td>61 (32.4%)</td>
<td>19 (42.2%)</td>
<td>42 (29.4%)</td>
<td>24 (25.5%)</td>
<td>18 (36.7%)</td>
<td>7 (41.2%)</td>
</tr>
<tr>
<td>Between 35 and 39</td>
<td>49 (26.1%)</td>
<td>13 (28.9%)</td>
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<td>27 (28.7%)</td>
<td>9 (18.4%)</td>
<td>3 (17.6%)</td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
<td>94 (100%)</td>
<td>49 (100%)</td>
<td>17 (100%)</td>
</tr>
<tr>
<td><strong>Relationship status at diagnosis</strong></td>
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<td></td>
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<tr>
<td>Single, never married</td>
<td>68 (36.2%)</td>
<td>16 (35.6%)</td>
<td>52 (36.4%)</td>
<td>37 (39.4%)</td>
<td>15 (30.6%)</td>
<td>5 (29.4%)</td>
</tr>
<tr>
<td>Married or partnered</td>
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<td>27 (60%)</td>
<td>88 (61.5%)</td>
<td>55 (58.5%)</td>
<td>33 (67.3%)</td>
<td>12 (70.6%)</td>
</tr>
<tr>
<td>Separated or divorced</td>
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<td>2 (4.4%)</td>
<td>3 (2.1%)</td>
<td>2 (2.1%)</td>
<td>1 (2%)</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
<td>94 (100%)</td>
<td>49 (100%)</td>
<td>17 (100%)</td>
</tr>
<tr>
<td><strong>Children status at diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>No</td>
<td>114 (60.6%)</td>
<td>23 (51.1%)</td>
<td>91 (63.6%)</td>
<td>54 (57.4%)</td>
<td>37 (75.5%)</td>
<td>16 (94.1%)</td>
</tr>
<tr>
<td>One child</td>
<td>42 (22.3%)</td>
<td>9 (20%)</td>
<td>33 (23.1%)</td>
<td>21 (22.3%)</td>
<td>12 (24.5%)</td>
<td>1 (5.9%)</td>
</tr>
<tr>
<td>Two children</td>
<td>27 (14.4%)</td>
<td>10 (22.2%)</td>
<td>17 (11.9%)</td>
<td>17 (18.1%)</td>
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<td>0</td>
</tr>
<tr>
<td>Three or more children</td>
<td>5 (2.7%)</td>
<td>3 (6.7%)</td>
<td>2 (1.4%)</td>
<td>2 (2.1%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
<td>94 (100%)</td>
<td>49 (100%)</td>
<td>17 (100%)</td>
</tr>
<tr>
<td><strong>Annual income at diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer diagnosis</td>
<td>All n=188 (%)</td>
<td>No discussion n=45 (%)</td>
<td>Had a fertility discussion with oncologists n=143 (%)</td>
<td>Did not consult a fertility specialist following a discussion n=94 (%)</td>
<td>Consulted a fertility specialist following a discussion n=49 (%)</td>
<td>Proceeded with fertility preservation n=17 (%)</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------</td>
<td>------------------------</td>
<td>-----------------------------------------------------</td>
<td>--------------------------------------------------------------------</td>
<td>----------------------------------------------------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Breast</td>
<td>72 (38.3%)</td>
<td>15 (33.3%)</td>
<td>57 (39.9%)</td>
<td>32 (34%)</td>
<td>25 (51%)</td>
<td>9 (52.9%)</td>
</tr>
<tr>
<td>Cervical</td>
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<td>5 (11.1%)</td>
<td>19 (13.3%)</td>
<td>12 (12.8%)</td>
<td>7 (14.3%)</td>
<td>3 (17.6%)</td>
</tr>
<tr>
<td>Gastrointestinal</td>
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<td>1 (2.2%)</td>
<td>5 (3.5%)</td>
<td>3 (3.2%)</td>
<td>2 (4.1%)</td>
<td>1 (5.9%)</td>
</tr>
<tr>
<td>Head and neck</td>
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<td>2 (1.4%)</td>
<td>1 (1.1%)</td>
<td>1 (2%)</td>
<td>1 (5.9%)</td>
</tr>
<tr>
<td>Hodgkin lymphoma</td>
<td>15 (8%)</td>
<td>4 (8.9%)</td>
<td>11 (7.7%)</td>
<td>7 (7.4%)</td>
<td>4 (8.2%)</td>
<td>1 (5.9%)</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>9 (4.8%)</td>
<td>1 (2.2%)</td>
<td>8 (5.6%)</td>
<td>7 (7.4%)</td>
<td>1 (2%)</td>
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</tr>
<tr>
<td>Lung</td>
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<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Ovary</td>
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<td>2 (4.4%)</td>
<td>9 (6.3%)</td>
<td>6 (6.4%)</td>
<td>3 (6.1%)</td>
<td>0</td>
</tr>
<tr>
<td>Cancer Type</td>
<td>Stage 1 (30.3%)</td>
<td>Stage 2 (32.4%)</td>
<td>Stage 3 (22.9%)</td>
<td>Stage 4 (6.4%)</td>
<td>Not specified (8%)</td>
<td>Total (100%)</td>
</tr>
<tr>
<td>-------------------</td>
<td>-----------------</td>
<td>-----------------</td>
<td>-----------------</td>
<td>----------------</td>
<td>-------------------</td>
<td>--------------</td>
</tr>
<tr>
<td>Pancreas</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
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<tr>
<td>Sarcoma</td>
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<td>5 (3.5%)</td>
<td>4 (4.3%)</td>
<td>1 (2%)</td>
<td>1 (5.9%)</td>
</tr>
<tr>
<td>Skin</td>
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<td>2 (4.4%)</td>
<td>1 (0.7)</td>
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<td>0</td>
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<tr>
<td>Thyroid</td>
<td>17 (9%)</td>
<td>8 (17.8%)</td>
<td>9 (6.3%)</td>
<td>6 (6.4%)</td>
<td>3 (6.1%)</td>
<td>0</td>
</tr>
<tr>
<td>Uterus</td>
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<td>0</td>
<td>4 (2.8%)</td>
<td>4 (4.3%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Urologic</td>
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<td>1 (2.2%)</td>
<td>2 (1.4%)</td>
<td>2 (2.1%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Leukemia</td>
<td>13 (6.9%)</td>
<td>3 (6.7%)</td>
<td>1 (0.7%)</td>
<td>8 (8.5%)</td>
<td>2 (4.1%)</td>
<td>1 (5.9%)</td>
</tr>
<tr>
<td>Carcinoma</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>1 (1.1%)</td>
<td>0</td>
</tr>
<tr>
<td>Others</td>
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<td>10 (7%)</td>
<td>1 (1.1%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>188 (110%)</strong></td>
<td><strong>45 (100%)</strong></td>
<td><strong>143 (100%)</strong></td>
<td><strong>94 (100%)</strong></td>
<td><strong>49 (100%)</strong></td>
<td><strong>17 (100%)</strong></td>
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</table>

**Cancer stage**

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<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
<th>Not specified</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>57 (30.3%)</td>
<td>61 (32.4%)</td>
<td>43 (22.9%)</td>
<td>12 (6.4%)</td>
<td>15 (8%)</td>
<td>188 (100%)</td>
</tr>
<tr>
<td>15 (33.3%)</td>
<td>16 (35.6%)</td>
<td>7 (15.6%)</td>
<td>3 (6.7%)</td>
<td>4 (8.9%)</td>
<td>45 (100%)</td>
</tr>
<tr>
<td>42 (29.4%)</td>
<td>45 (31.5%)</td>
<td>36 (25.2%)</td>
<td>9 (6.3%)</td>
<td>11 (7.7%)</td>
<td>143 (100%)</td>
</tr>
<tr>
<td>31 (33%)</td>
<td>27 (28.7%)</td>
<td>23 (24.5%)</td>
<td>4 (4.3%)</td>
<td>9 (9.6%)</td>
<td>94 (100%)</td>
</tr>
<tr>
<td>11 (22.4%)</td>
<td>18 (36.7%)</td>
<td>13 (26.5%)</td>
<td>5 (10.2%)</td>
<td>2 (4.1%)</td>
<td>49 (100%)</td>
</tr>
<tr>
<td>3 (17.6%)</td>
<td>5 (29.4%)</td>
<td>5 (29.4%)</td>
<td>3 (17.6%)</td>
<td>1 (5.9%)</td>
<td>17 (100%)</td>
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**Cancer treatment**

<table>
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<tr>
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<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
<th>Not specified</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery (Yes or No)</td>
<td>143 (76.1%)</td>
<td>36 (80%)</td>
<td>107 (74.8%)</td>
<td>69 (73.4%)</td>
<td>38 (77.6%)</td>
<td>188 (100%)</td>
</tr>
<tr>
<td>Chemotherapy (Yes or No)</td>
<td>136 (72.3%)</td>
<td>25 (55.6%)</td>
<td>111 (77.6%)</td>
<td>68 (72.3%)</td>
<td>43 (87.8%)</td>
<td>188 (100%)</td>
</tr>
<tr>
<td>Radiation therapy (Yes or No)</td>
<td>100 (53.2%)</td>
<td>27 (60%)</td>
<td>73 (51%)</td>
<td>43 (45.7%)</td>
<td>30 (61.2%)</td>
<td>188 (100%)</td>
</tr>
<tr>
<td>Stem cell transplantation (Yes or No)</td>
<td>10 (5.3%)</td>
<td>2 (4.4%)</td>
<td>8 (5.6%)</td>
<td>6 (6.4%)</td>
<td>2 (4.1%)</td>
<td>10 (5.9%)</td>
</tr>
<tr>
<td>Others</td>
<td>40 (21.3%)</td>
<td>9 (20%)</td>
<td>31 (21.7%)</td>
<td>19 (20.2%)</td>
<td>12 (24.5%)</td>
<td>3 (17.6%)</td>
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</tbody>
</table>

**Oncologists involved in care**

<table>
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<tr>
<th>Oncologist</th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
<th>Not specified</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgical oncologist (Yes or No)</td>
<td>100 (53.2%)</td>
<td>26 (57.8%)</td>
<td>74 (51.7%)</td>
<td>30 (61.2%)</td>
<td>30 (61.2%)</td>
<td>12 (70.6%)</td>
</tr>
<tr>
<td>Medical oncologist (Yes or No)</td>
<td>134 (71.3%)</td>
<td>28 (62.2%)</td>
<td>106 (74.1%)</td>
<td>36 (73.5%)</td>
<td>36 (73.5%)</td>
<td>12 (70.6%)</td>
</tr>
<tr>
<td>Radiation oncologist (Yes or No)</td>
<td>105 (55.9%)</td>
<td>25 (55.6%)</td>
<td>80 (55.9%)</td>
<td>33 (67.3%)</td>
<td>33 (67.3%)</td>
<td>13 (76.5%)</td>
</tr>
<tr>
<td>Gynecologic oncologist (Yes or No)</td>
<td>46 (24.5%)</td>
<td>10 (22.2%)</td>
<td>36 (25.2%)</td>
<td>13 (26.5%)</td>
<td>13 (26.5%)</td>
<td>2 (11.8%)</td>
</tr>
<tr>
<td>Hematologist</td>
<td>7 (3.7%)</td>
<td>2 (4.4%)</td>
<td>5 (3.5%)</td>
<td>2 (4.1%)</td>
<td>1 (2%)</td>
<td>1 (5.9%)</td>
</tr>
<tr>
<td>Endocrinologist</td>
<td>7 (3.7%)</td>
<td>3 (6.7%)</td>
<td>4 (2.8%)</td>
<td>1 (2%)</td>
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</tbody>
</table>

**Fertility concern at diagnosis (5-point Likert Scale)**

<table>
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<tr>
<th>Concern Level</th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
<th>Not specified</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not concerned at all (1)</td>
<td>27 (14.4%)</td>
<td>13 (28.9%)</td>
<td>14 (9.8%)</td>
<td>13 (13.8%)</td>
<td>1 (2%)</td>
<td>0</td>
</tr>
<tr>
<td>Not quite concerned (2)</td>
<td>24 (12.8%)</td>
<td>7 (15.6%)</td>
<td>17 (11.9%)</td>
<td>13 (13.8%)</td>
<td>4 (8.2%)</td>
<td>0</td>
</tr>
<tr>
<td>Somewhat concerned (3)</td>
<td>21 (11.2%)</td>
<td>10 (22.2%)</td>
<td>11 (7.7%)</td>
<td>6 (6.4%)</td>
<td>5 (10.2%)</td>
<td>1 (5.9%)</td>
</tr>
<tr>
<td>Quite concerned (4)</td>
<td>30 (16%)</td>
<td>6 (13.3%)</td>
<td>24 (16.8%)</td>
<td>17 (18.1%)</td>
<td>7 (14.3%)</td>
<td>1 (5.9%)</td>
</tr>
<tr>
<td>Very concerned (5)</td>
<td>86 (45.7%)</td>
<td>9 (20%)</td>
<td>77 (53.8%)</td>
<td>45 (47.9%)</td>
<td>32 (65.3%)</td>
<td>15 (88.2%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>188 (100%)</strong></td>
<td><strong>45 (100%)</strong></td>
<td><strong>143 (100%)</strong></td>
<td><strong>94 (100%)</strong></td>
<td><strong>49 (100%)</strong></td>
<td><strong>17 (100%)</strong></td>
</tr>
</tbody>
</table>

*Participants can select multiple categories*
The first research question examines the factors associated with young cancer patients having a fertility discussion with their oncologists at the time of cancer diagnosis (Figure 3). The full sample was used for analysis (n=188). Pearson $\chi^2$ was conducted for bivariate analyses to examine the association of categorical variables. Logistic regression analyses were used to investigate the odds of having a fertility discussion with oncologists. The findings of the first research question were reported in Chapter 2, which is a stand-alone paper.

The second research question examines the factors associated with young cancer patients consulting a fertility specialist following a fertility discussion with their oncologists (Figure 3). To answer this research question, only the participants who had a fertility discussion with their oncologists were used for analysis (n=143). Pearson $\chi^2$ was conducted to examine the bivariate relationships of variables. Logistic regression analysis was used to examine factors associated with consulting a fertility specialist to discuss fertility preservation options. Thematic analysis was used to analyze the descriptive comments (Boyatzis et al., 1998; Strauss & Corbin, 1998). The findings of this second research question are reported in Chapter 3, which is a stand-alone paper.

The third research question examines the factors associated with the uptake of a fertility preservation procedure following a fertility preservation consultation with a specialist (Figure 3). To answer this research question, only the participants who received a fertility preservation consultation were used for analysis (n=49). Pearson $\chi^2$ and Spearman’s correlation were conducted to examine the bivariate relationships between variables. Logistic regression was used to analyze the factors associated with the odds of proceeding with fertility preservation after seeing a fertility specialist. Univariate logistic regression was conducted first to evaluate the odds of proceeding with fertility preservation procedure for each variable. Multivariate logistic regression was then conducted using the variables that were significant at $p<.20$ in univariate analyses. One-way ANOVA was used to investigate the oncologist's role in supporting participants making a high quality fertility preservation decision. The findings of this third research question are reported in Chapter 4, which is also a stand-alone paper.
Chapter 5 is the concluding chapter that synthesizes the major findings of the three research questions. The findings of this study provide evidence to validate the synthesized decision-making theoretical framework. Implication for practice and future research directions are also discussed in this final chapter.
Figure 3: Three research questions to test the Integrated Fertility Preservation Decision-Making Framework

STAGE 1: Antecedents

STAGE 2: Fertility Risk Awareness

STAGE 3: In-Person Fertility Risk Appraisal

STAGE 4: Fertility Preservation Awareness

STAGE 5: Fertility Preservation Decision-Making

Full sample n=188

STAGE 1: Antecedents

- Socio-demographic characteristics
- Cancer profile
- Treatment decision making styles

STAGE 2: Fertility Risk Awareness

- Personalized medical information
- Medical consultation with oncologists
- Had a fertility discussion (n=143)
- No discussion (n=45)

STAGE 3: In-Person Fertility Risk Appraisal

- Awareness of cancer treatment-induced fertility
- Had a fertility discussion
- Uninformed decision

STAGE 4: Fertility Preservation Awareness

- Self-in-situation fertility risk appraisal
- Primary appraisal
- Had a referral
- Secondary appraisal
- No referral

STAGE 5: Fertility Preservation Decision-Making

- Fertility preservation option appraisal
- Fertility preservation attitudes and knowledge

Full sample n=188

Paper 1: What are the factors associated with having a fertility discussion with oncologists (n=188, 45 versus 143)

Paper 2: What are the factors associated with receiving a fertility preservation consultation (n=143, 94 versus 49)

Paper 3: What are the factors associated with the uptake of fertility preservation procedure (n=49, 32 versus 17)

Proceded n=17

Not to proceed n=32

1. Perceived severity
2. Perceived personal susceptibility
3. Perceived benefits
4. Perceived barriers
5. Cue for action from oncologists
CHAPTER 2
Factors associated with having a fertility discussion with oncologists

2.1 Abstract

Background: Little is known about the extent to which young Canadian women are counselled by their oncologists about the potential fertility risks associated with their cancer treatment at the time of cancer diagnosis. This paper examines the factors associated with female cancer patients having a fertility discussion with oncologists prior to commencing cancer treatment. To our knowledge, this is the first study that distinguish the differences between oncologist-initiated versus patient-initiated fertility discussions in statistical analyses.

Methods: Participants were recruited through cancer organizations, survivor networks, and digital media. Survey participants were 188 young women who received a cancer diagnosis after the year 2000 and were between the ages of 18 and 39 at that time, and had finished active cancer treatment by the time of the survey (2012-2013). Pearson $\chi^2$ and logistic regression analyses were used for analyses.

Results: Participants’ mean age at cancer diagnosis was 30.2 years (SD=5.7). A quarter of participants (n=45, 23.9%) did not have a fertility discussion with any oncologists. Of the three quarters (n=143, 76.1%) who had a fertility discussion with their oncologists, discussions were equally initiated by oncologists (n=71) and patients (n=72). The only significant predictor associated with cancer patients having a fertility discussion with oncologists, irrespective of whether the discussion was oncologist- or patient-initiated, was their concern about fertility ($p<.001$). However, when the fertility discussions were initiated by oncologists and were unprompted by their patients, the only significant predictor was the time frame of cancer diagnosis ($p<.05$). In addition, 42% of women diagnosed with cancer after 2006 had an oncologist-initiated fertility discussion compared with only 13% of women diagnosed with cancer between 2000 and 2006.
Conclusions: A positive shift in practice behaviors was evident through a threefold increase of cancer patients receiving oncologist-initiated fertility discussion after 2006. The findings confirm the crucial role played by oncologists in communicating with cancer patients the potential treatment-induced fertility risks through the provision of personalized medical information.
2.2 Introduction

Latest Canadian statistics suggest that approximately 18,000 women are newly diagnosed with cancers each year. Among them, nearly 5,000 are between the ages of 20 and 39. Unfortunately, females have a substantially higher risk of developing invasive cancers from birth to age 49 than males (5.4% versus 3.5%) (Canadian Cancer Society, 2014). Although survival rates are high due to advances in cancer treatments, reproductive functions are susceptible to the potential deleterious side effects of cancer therapy. Many premenopausal women are at risk of infertility after completing their cancer treatment. Practice guidelines published by medical oncology societies in the UK, US, Australia, and the Netherlands underscore the clinical responsibilities of oncologists to routinely inform all premenopausal women about the fertility risks associated with cancer treatments, and making timely fertility preservation (FP) referrals for concerned individuals (COSA, 2011; Lee et al., 2006; Loren et al., 2013; Louwé et al., 2013; NICE, 2014).

Despite the recommendations by oncology medical societies to standardize FP practice in cancer care, extant data suggest that fertility information is far from being offered routinely to all young women at cancer diagnosis. Two systematic reviews conclude that the percentages of young cancer patients being informed about the impact of cancer treatment on fertility by oncology health care providers ranges from 34% to 72% (Tschudin & Bitzer, 2009), and from zero to 85% (Goossens et al., 2014). Numerous studies have also found gender differences in the receipt of cancer-related fertility information, and female cancer patients are less likely to be informed by oncology health providers about their treatment-induced fertility risks before commencing cancer treatments compared with males (Armuand et al., 2012; Mancini, et al., 2008; Yeomanson, Morgan, & Pacey, 2013). Often fertility discussions would not have occurred if patients did not initiate the discussion with their oncologists (Shimizu et al., 2013). Surveys on oncologist attitudes and practice behaviors related to FP also found that oncologists were inconsistent and selective in discussing fertility concerns with their cancer patients (Duffy, Allen, Dube, & Dickersin, 2012; Quinn et al., 2009). Furthermore, the prevalence of fertility discussions provided by oncologists seems to be influenced by physician factors (Forman et al., 2010), patient characteristics (Geue et al., 2014; Sobota & Ozakinci, 2014), logistic constraints (Quinn et al, 2008), and and practice cultures.
To date, little is known about the extent to which young Canadian women are counselled by their oncologists about their treatment-induced fertility risks and their FP options before initiating cancer treatment. The percentage of Canadian female cancer patients who had a fertility discussion with their oncologists at the time of diagnosis is not yet known. However, we do know that almost three quarters of oncologists in one Canadian study indicated that they rarely or never modified cancer treatment despite the associated fertility risks (Yee et al., 2012d).

This paper examines the factors associated with female cancer patients having a fertility discussion with their oncologists at the time of cancer diagnosis. To our knowledge, this is the first study examining the factors associated with Canadian female cancer patients having a fertility discussion that was initiated by oncologists without patient prompting.

2.3 Methods

2.3.1 Study design

The study was approved by the research ethics board of the University of Toronto. Eligible participants were women who were diagnosed with cancer since January 2000, and were between the ages of 18 and 39 at that time. By the time of the survey they had to have completed active cancer treatment such as chemotherapy, stem cell transplantation, and radiation.

About 50 cancer groups helped promote the study by disseminating the recruitment flyers and posting the study’s website domain and survey’s URL through their channels. In addition, advertising websites (i.e. Kijiji, Cragslist) and social media platforms (i.e. Facebook, Twitter) were used to reach out to potential participants. Participants were not directly rewarded for survey completion but were offered a monthly draw to win one of the five $20 electronic gift cards. During the 10-month data collection period from September 2012 to June 2013, approximately 250 women accessed the online survey. A total of 188 completed surveys were used for analyses.
2.3.2 Measures

The web-based survey was comprised of 115 questions. Two independent experts in survey design, and one expert in fertility preservation were consulted during the process of survey construction. Nine young female cancer survivors recruited through two cancer organizations\(^2\) pilot-tested the online survey for content validity and readability. Variables used for analyses in this paper were: 1) Socio-demographic characteristics at cancer diagnosis: items included age, ethnicity, residence, education, income, motherhood status, and relationship status; 2) Cancer profiles: items included years since diagnosis, cancer type, type of cancer treatment, and level of fertility concern at diagnosis and 3) Fertility discussion: items included whether having a fertility discussion or not with oncologists, and who initiated the discussion.

2.3.3 Data analysis

Data analyses were conducted using the Statistical Package for the Social Sciences (SPSS) version 22.0. Participants were divided into groups based on the types of fertility discussion they had or not had with their oncologists: 1) had a discussion versus no discussion; 2) had an oncologist-initiated discussion versus no discussion or had a patient-initiated discussion. The 5-point Likert scale fertility concern variable was collapsed into a three-point variable of ‘low concern’ (i.e. ‘not concerned at all’, ‘not quite concerned’), ‘medium concern’ (i.e. ‘somewhat concerned’), and ‘high concern’ (i.e. ‘quite concerned’ and ‘very concerned’). Pearson χ\(^2\) was used for bivariate analyses to examine the association of categorical variables. Logistic regression analyses were conducted to investigate the odds of 1) having a pre-cancer treatment fertility discussion with oncologists irrespective of whether the discussion was oncologist- or patient-initiated (yes/no), and 2) having a pre-cancer fertility discussion that was initiated by oncologists without patient prompting (yes/no).

A total of eleven predictors were entered into 3 blocks: socio-demographic characteristics at cancer diagnosis for Block 1, cancer profiles for Block 2, and fertility concern at cancer diagnosis

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for Block 3. The Hosmer and Lemeshow’s goodness-of-fit test in each block was checked to ensure the estimates fit the data at an acceptable level \((p>.05)\). A 95% confidence interval (CI) was generated for odds ratios (OR).

### 2.4 Results

The socio-demographic characteristics of the 188 female cancer survivors who completed the web-based questionnaire are presented in Table 4. Their mean age at cancer diagnosis was 30.2 years (SD=5.7). More than half \((n=104, 55.3\%)\) were between the ages of 25 and 34 when a diagnosis was received. Of the 74 women \((39.4\%)\) who had a child prior to receiving their diagnosis, 21 indicated that they had completed their family at the time of cancer diagnosis, although their family building plan could be changed post-cancer treatment with new circumstances. Of the 114 women \((60.6\%)\) who were childless, 4 indicated that they never wanted to have children. Participants who had no procreation plan following cancer treatment only represented 13.3% of the full sample. Almost 80% of participants had cancer treatments involving chemotherapy, radiation, and stem cell transplantation that have known threats to women’s fertility.

One quarter of participants \((n=45, 23.9\%)\) did not recall having a fertility discussion with any doctors, including their oncologists, at the time of cancer diagnosis. Of the three quarters \((n=143, 76.1\%)\) who had a fertility discussion with their oncologists, half \((n=71)\) of the discussions were oncologist-initiated, and the other half \((n=72)\) were patient-initiated.

#### 2.4.1 Having a fertility discussion with oncologists \((n=188, 45 versus 143)\)

The characteristics of cancer survivors who did not receive any fertility information were compared with those who had a pre-cancer treatment fertility discussion with their oncologists \((45 versus 143)\). As shown in Table 4, cancer patients who had a fertility discussion were more likely to report having a high fertility concern at diagnosis compared with those who had no discussion \((70.6\% versus 33.3\%, p<.001)\). The ‘no discussion’ group also had a disproportionately high number of participants with low fertility concern \((44.4\% versus 21.7\%, p<.001)\) and medium fertility concern \((22.2\% versus 7.7\%, p<.001)\), compared with the ‘fertility discussion’ group.
Table 4: Characteristics of 188 survey participants and logistic regression analysis of having a fertility discussion with oncologists (n=188, 45 versus 143)

<table>
<thead>
<tr>
<th>BLOCK 1: Socio-demographics at diagnosis</th>
<th>All n=188 (%)</th>
<th>No fertility discussion n=45 (%)</th>
<th>Had fertility discussion n=143 (%)</th>
<th>χ² p-value</th>
<th>Model 1 OR (95% CI)</th>
<th>Model 2 OR (95% CI)</th>
<th>Model 3 OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td>0.21</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between 18 and 24</td>
<td>35 (18.6%)</td>
<td>7 (15.6%)</td>
<td>28 (19.6%)</td>
<td>1.37 (.38 to 4.88)</td>
<td>1.74 (.46 to 6.62)</td>
<td>1.01 (.24 to 4.28)</td>
<td></td>
</tr>
<tr>
<td>Between 25 and 29</td>
<td>43 (22.9%)</td>
<td>6 (13.3%)</td>
<td>37 (25.9%)</td>
<td>2.20 (.71 to 6.81)</td>
<td>2.54 (.78 to 8.23)</td>
<td>1.87 (.52 to 6.71)</td>
<td></td>
</tr>
<tr>
<td>Between 30 and 34</td>
<td>61 (32.4%)</td>
<td>19 (42.2%)</td>
<td>42 (29.4%)</td>
<td>.71 (.30 to 1.68)</td>
<td>.76 (.31 to 1.88)</td>
<td>.52 (.19 to 1.44)</td>
<td></td>
</tr>
<tr>
<td>Between 35 and 39</td>
<td>49 (26.1%)</td>
<td>13 (28.9%)</td>
<td>36 (25.2%)</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
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<td></td>
<td>.61</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>163 (86.7%)</td>
<td>38 (84.4%)</td>
<td>125 (87.4%)</td>
<td>1.76 (.62 to 5.02)</td>
<td>1.90 (.66 to 5.48)</td>
<td>1.74 (.55 to 5.5)</td>
<td></td>
</tr>
<tr>
<td>Non-white</td>
<td>25 (13.3%)</td>
<td>7 (15.6%)</td>
<td>18 (12.6%)</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residence</td>
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<td></td>
<td></td>
<td>.43</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metro or urban city</td>
<td>134 (71.3%)</td>
<td>30 (66.7%)</td>
<td>104 (72.7%)</td>
<td>1.49 (.68 to 3.26)</td>
<td>1.56 (.70 to 3.47)</td>
<td>1.22 (.51 to 2.89)</td>
<td></td>
</tr>
<tr>
<td>Major town or rural area</td>
<td>54 (28.7%)</td>
<td>15 (33.3%)</td>
<td>39 (27.3%)</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Highest education</td>
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<td></td>
<td></td>
<td>.54</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No university degree</td>
<td>64 (34%)</td>
<td>17 (37.8%)</td>
<td>47 (32.9%)</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>University degree</td>
<td>124 (65.9%)</td>
<td>28 (62.2%)</td>
<td>96 (70.6%)</td>
<td>1.28 (.61 to 2.71)</td>
<td>1.37 (.63 to 2.97)</td>
<td>1.34 (.58 to 3.10)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual income</td>
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<td></td>
<td></td>
<td>.73</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;= $30,000</td>
<td>54 (28.7%)</td>
<td>12 (26.7%)</td>
<td>42 (29.4%)</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>&gt; $30,000</td>
<td>134 (71.3%)</td>
<td>33 (73.3%)</td>
<td>101 (70.6%)</td>
<td>.83 (.32 to 2.20)</td>
<td>.75 (.28 to 2.02)</td>
<td>.86 (.29 to 2.55)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had a child</td>
<td></td>
<td></td>
<td></td>
<td>.13</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>74 (39.4%)</td>
<td>22 (48.9%)</td>
<td>52 (36.4%)</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>114 (60.6%)</td>
<td>23 (51.1%)</td>
<td>91 (63.6%)</td>
<td>1.42 (.60 to 3.37)</td>
<td>1.26 (.52 to 3.05)</td>
<td>1.42 (.53 to 3.81)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had a partner</td>
<td></td>
<td></td>
<td></td>
<td>.85</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>115 (61.2%)</td>
<td>27 (60%)</td>
<td>88 (61.5%)</td>
<td>1.61 (.68 to 3.85)</td>
<td>1.50 (.61 to 3.63)</td>
<td>1.44 (.55 to 3.75)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>73 (38.8%)</td>
<td>18 (40%)</td>
<td>55 (38.5%)</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>45 (100%)</td>
<td>143 (100%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BLOCK 2: Cancer profiles*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years since diagnosis</td>
<td></td>
<td></td>
<td></td>
<td>.85</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;= 3 years</td>
<td>107 (56.9%)</td>
<td>24 (53.3%)</td>
<td>83 (58%)</td>
<td>---</td>
<td>1.0</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>4-6 years</td>
<td>51 (27.1%)</td>
<td>13 (28.9%)</td>
<td>38 (26.6%)</td>
<td>---</td>
<td>.88 (.39 to 2.00)</td>
<td>1.12 (.47 to 2.67)</td>
<td></td>
</tr>
<tr>
<td>&gt;= 7 years</td>
<td>30 (16%)</td>
<td>8 (17.8%)</td>
<td>22 (15.4%)</td>
<td>---</td>
<td>.64 (.22 to 1.83)</td>
<td>.57 (.18 to 1.81)</td>
<td></td>
</tr>
</tbody>
</table>


Table 4 also reports the logistic regression analysis of the odds of having a pre-cancer treatment fertility discussion with oncologists. The final model predicts 23.1% of the variance. The only significant variable was having a high degree of fertility concern at diagnosis \((p<.01)\), and this variable alone explains 14.5% of the variance. After taking into account all other predictors used in the analyses, women who had a high level of fertility concern at diagnosis were five times more likely to have a fertility discussion with their oncologists than those who had a low level of fertility concern.

2.4.2 Having an oncologist-initiated fertility discussion (n=188, n=117 versus n=71)

The proportion of women who either did not have a fertility discussion or whose discussion was self-initiated was compared with those who had an oncologist-initiated fertility discussion (117 versus 71). As shown in Table 5, significantly more women in the oncologist-initiated
discussion group were diagnosed in the past 3 years before survey time (62% versus 53.8%, p<.05) or diagnosed between 4 and 6 years before survey time (32.4% versus 23.9%, p<.05), and at the time of diagnosis, had a partner (70.4% versus 55.6%, p<.05), earned an annual income above $30,000 (81.7% versus 65%, p<.05), and had gonadotoxic cancer treatments (87.3% versus 74.4%, p<.05) than the women in the other group. In addition, we found that 42% of women diagnosed with cancer after 2006 had an oncologist-initiated fertility discussion compared to only 13% of women who had cancer between 2000 and 2006.

The same 11 variables used in the previous logistic regression analysis were run, but with a different dependent variable to analyze the odds of having an oncologist-initiated fertility discussion without patient prompting (Table 5). The only significant predictor was the year since cancer diagnosis (p<.05) and none of the socio-demographic characteristics at diagnosis was significant in predicting the occurrence of an oncologist-initiated discussion. The final model explains 17.7% of the variance. Women who had cancer within the past six years before survey completion had more than three times the odds of having an oncologist-initiated fertility discussion, compared with women who were diagnosed more than 7 years ago. Unlike the previous logistic regression analysis, having a high degree of fertility concern was not significant in predicting the odds of having a discussion that was initiated by oncologists. The percentage of variance explained by the levels of fertility concern dropped from 14.5% in the previous analysis to 0.7% in the current model when oncologists initiated the fertility discussion without patient prompting.

Table 5: Characteristics of 188 survey participants and logistic regression analysis of having an oncologist-initiated fertility discussion (n=188, 117 versus 71)

<table>
<thead>
<tr>
<th>BLOCK 1: Socio-demographics at diagnosis</th>
<th>All n=188 (%)</th>
<th>No discussion or had self-initiated discussion n=117 (%)</th>
<th>Had oncologist-initiated discussion n=71 (%)</th>
<th>χ² p-value</th>
<th>Model 1 OR (95% CI)</th>
<th>Model 2 OR (95% CI)</th>
<th>Model 3 OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between 18 and 24</td>
<td>35 (18.6%)</td>
<td>25 (21.4%)</td>
<td>10 (14.1%)</td>
<td>1.37 (.38 to 4.88)</td>
<td>.90 (.25 to 3.22)</td>
<td>.98 (.27 to 3.61)</td>
<td></td>
</tr>
<tr>
<td>Between 25 and 29</td>
<td>43 (22.9%)</td>
<td>25 (21.4%)</td>
<td>18 (25.4%)</td>
<td>2.20 (.71 to 6.81)</td>
<td>.81 (.30 to 2.16)</td>
<td>.89 (.33 to 2.42)</td>
<td></td>
</tr>
</tbody>
</table>
### Ethnicity

<table>
<thead>
<tr>
<th></th>
<th>Between 30 and 34</th>
<th>Between 35 and 39</th>
<th>Total</th>
<th>95% CI</th>
<th>95% CI</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>163 (86.7%)</td>
<td>100 (85.5%)</td>
<td>263 (88.7%)</td>
<td>1.15 (.43 to 3.03)</td>
<td>1.90 (.66 to 5.48)</td>
<td>1.32 (.48 to 3.65)</td>
</tr>
<tr>
<td>Non-white</td>
<td>25 (13.3%)</td>
<td>17 (14.5%)</td>
<td>42 (11.3%)</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>117 (100%)</td>
<td>71 (100%)</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
</tbody>
</table>

### Residence

<table>
<thead>
<tr>
<th></th>
<th>Metropolitan or urban city</th>
<th>Major town or rural area</th>
<th>Total</th>
<th>95% CI</th>
<th>95% CI</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Metropolis</td>
<td>134 (71.3%)</td>
<td>54 (28.7%)</td>
<td>188 (100%)</td>
<td>.79 (.39 to 1.61)</td>
<td>1.56 (.70 to 3.47)</td>
<td>.86 (.41 to 1.82)</td>
</tr>
<tr>
<td>Major town</td>
<td>32 (24.7%)</td>
<td>22 (31%)</td>
<td>54 (28.7%)</td>
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<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>117 (100%)</td>
<td>71 (100%)</td>
<td>1.0</td>
<td>1.0</td>
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</tr>
</tbody>
</table>

### Highest education

<table>
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<tr>
<th></th>
<th>No university degree</th>
<th>University degree</th>
<th>Total</th>
<th>95% CI</th>
<th>95% CI</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>No university</td>
<td>64 (34%)</td>
<td>124 (65.9%)</td>
<td>188 (100%)</td>
<td>.87 (.44 to 1.72)</td>
<td>1.04 (.51 to 2.14)</td>
<td>1.06 (.51 to 2.17)</td>
</tr>
<tr>
<td>University</td>
<td>40 (34.2%)</td>
<td>77 (65.8%)</td>
<td>117 (100%)</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>117 (100%)</td>
<td>71 (100%)</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
</tbody>
</table>

### Income

<table>
<thead>
<tr>
<th></th>
<th>&lt;= $30,000</th>
<th>&gt; $30,000</th>
<th>Total</th>
<th>95% CI</th>
<th>95% CI</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;= $30,000</td>
<td>54 (28.7%)</td>
<td>41 (35%)</td>
<td>95 (50%)</td>
<td>2.20 (.88 to 5.54)</td>
<td>2.10 (.76 to 5.80)</td>
<td>2.0 (.72 to 5.59)</td>
</tr>
<tr>
<td>&gt; $30,000</td>
<td>134 (71.3%)</td>
<td>76 (65%)</td>
<td>210 (100%)</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>117 (100%)</td>
<td>71 (100%)</td>
<td>1.0</td>
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### Had a child

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<th>95% CI</th>
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<tr>
<td>Yes</td>
<td>74 (39.4%)</td>
<td>48 (41%)</td>
<td>122 (65%)</td>
<td>1.79 (.83 to 3.84)</td>
<td>1.92 (.86 to 4.30)</td>
<td>1.98 (.88 to 4.46)</td>
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<td>No</td>
<td>114 (60.6%)</td>
<td>69 (59%)</td>
<td>183 (100%)</td>
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<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>117 (100%)</td>
<td>71 (100%)</td>
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### Had a partner

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<th>95% CI</th>
<th>95% CI</th>
<th>95% CI</th>
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<tr>
<td>Yes</td>
<td>115 (61.2%)</td>
<td>65 (55.6%)</td>
<td>180 (100%)</td>
<td>1.79 (.83 to 3.84)</td>
<td>1.92 (.86 to 4.30)</td>
<td>1.98 (.88 to 4.46)</td>
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<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>117 (100%)</td>
<td>71 (100%)</td>
<td>1.0</td>
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### BLOCK 2: Cancer profiles

#### Years since diagnosis

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<th>&lt;= 3 years</th>
<th>4-6 years</th>
<th>&gt;= 7 years</th>
<th>Total</th>
<th>95% CI</th>
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<tr>
<td>&lt;= 3 years</td>
<td>107 (56.9%)</td>
<td>63 (53.8%)</td>
<td>44 (62%)</td>
<td>---</td>
<td>3.75^t (.13 to 6.39)</td>
<td>3.68^t (.10 to 6.17)</td>
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</tr>
<tr>
<td>4-6 years</td>
<td>51 (27.1%)</td>
<td>28 (23.9%)</td>
<td>23 (32.4%)</td>
<td>---</td>
<td>5.11^t (.44 to 18.20)</td>
<td>4.87^t (.35 to 17.54)</td>
<td></td>
</tr>
<tr>
<td>&gt;= 7 years</td>
<td>30 (16%)</td>
<td>26 (22.2%)</td>
<td>4 (5.6%)</td>
<td>---</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>117 (100%)</td>
<td>71 (100%)</td>
<td>1.0</td>
<td>1.0</td>
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</table>

#### Breast cancer

<table>
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<tr>
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<th>95% CI</th>
<th>95% CI</th>
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<tbody>
<tr>
<td>Yes</td>
<td>72 (38.3%)</td>
<td>42 (35.9%)</td>
<td>114 (61.2%)</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>No</td>
<td>116 (61.7%)</td>
<td>75 (64.1%)</td>
<td>191 (100%)</td>
<td>1.26 (.61 to 2.59)</td>
<td>1.24 (.60 to 2.57)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>188 (100%)</td>
<td>117 (100%)</td>
<td>71 (100%)</td>
<td>1.0</td>
<td>1.0</td>
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#### Cancer treatment types

<table>
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<tr>
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<th>Chemo, radiation or stem cell</th>
<th>95% CI</th>
<th>95% CI</th>
<th>95% CI</th>
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<tbody>
<tr>
<td>Chemo, radiation or stem cell</td>
<td>149 (79.3%)</td>
<td>87 (74.4%)</td>
<td>62 (87.3%)</td>
<td>2.31 (.94 to 5.7)</td>
</tr>
</tbody>
</table>
2.5 Discussions

2.5.1 No fertility discussion

Despite the recognized benefits for young female cancer patients to receive fertility information from their oncologists, one quarter of our survey participants reported not having had a fertility discussion with an oncologist prior to commencing their cancer treatment. This is disconcerting as the majority of our survey participants were young childless women in their prime childbearing years, and more than 80% had cancer treatments with potential deleterious effects on ovarian functions. Our finding of 24% is comparable with the percentages reported in two other web-based surveys, where 28% (Partridge et al., 2004) and 20% (Tschudin et al., 2010) of their female cancer survivors did not recall having any fertility discussion with their doctors at the time of cancer diagnosis. In comparison to these findings, other studies where the female respondents were recruited from cancer registries and oncology centers found much higher rates of not having had a discussion, with 66% (Duffy et al. 2005), 41% (Armuand et al., 2012), 40% (Geue et al., 2014), and 39% (Letourneau et al., 2012a) of respondents reporting not being counselled by any doctor on fertility matters prior to commencing cancer treatments. These variations may be due to differences in recruitment factors and sampling frame.
Patients are under considerable stress when a life-threatening cancer diagnosis is received. Providing all necessary medical information related to cancer treatments, including the side effects on fertility, is essential for cancer patients making informed medical decisions concerning their own health and long-term quality of life (Wilkes, Coulson, Crosland, Rubin, & Stewart, 2010; Zebrack, Casillas, Nohr, Adams, Zeltzer, 2004). A US survey found that fertility concerns influenced the choice of cancer treatments for almost one-third of the 657 surveyed breast cancer patients (Partridge et al., 2004), a finding also supported by qualitative studies (Gorman, Usita, Madlensky, & Pierce, 2011; R. J. Lee et al., 2011). Infertility has a negative impact on long-term quality of life for young women who survive cancer but have not yet completed their family at the time of diagnosis (Kondapalli et al., 2014). There are psychological benefits of receiving fertility information even under non-ideal circumstances, such as when a new cancer diagnosis is received and treatment plans need to be formulated urgently (Gorman, Malcarne, Roesch, Madlensky, & Pierce, 2010; Reh et al., 2011).

2.5.2 Having a fertility discussion with oncologists

We found that cancer patient fertility concern at diagnosis was a significant variable in both the bivariate and logistic regression analyses. Significantly more women who had a fertility discussion with their oncologists were very concerned about their fertility at the time of cancer diagnosis; being very concerned about fertility at cancer diagnosis was the only significant determinant in the logistic regression associated with increased odds of having a fertility discussion with oncologists, irrespective of who initiated the discussion. However, it is important to recognize that those who did not have a high fertility concern at cancer diagnosis may have lacked knowledge of fertility risks associated with their cancer treatment. Thus, the lack of fertility concern at diagnosis may not be due to a lack of desire to procreate. The fertility needs of young women are usually overshadowed by their cancer diagnosis when survival takes priority, but fertility concerns may increase over time when they move farther away from diagnosis (Gorman et al., 2010; Wilkes et al., 2010).
It is worrisome that half of the cancer patients had to initiate the fertility discussions with their oncologists when making plans for cancer treatment, and that they may not be counselled about their fertility risks had they not initiated the discussion. Similar observation was found in a Netherlands’ study (Garvelink et al., 2013) where one-third of the female participants self-initiated the fertility discussions with their oncologists. Perhaps women with high fertility needs are more likely to drive the discussion in order to clarify their concerns (Vadaparampil et al., 2012). A study by Shimizu and colleagues (2013) found that one in five of the surveyed 434 Japanese breast oncologists reported having fertility discussions only at patient requests. The right to receive all essential medical information concerning cancer treatments, including the late side effects on their fertility, should not be contingent on self-initiation and advocacy. Our findings suggest that assertive patients who have some prior fertility knowledge may have a better chance of receiving fertility information from oncologists. Conversely, women who are passive or emotionally preoccupied with their cancer diagnosis may not receive essential information if they do not bring up the topic themselves (Garvelink et al., 2013).

Oncologists may have the perception that patients are not interested in fertility matters if they do not raise the issue themselves (Quinn et al., 2009). Studies found that nearly one-third of the surveyed oncologists rarely took a woman’s fertility desire into consideration when planning cancer treatments (Forman et al., 2010; Ghorbani et al., 2011). Other studies examining oncologist attitudes on FP found that a quarter did not think it was their clinical responsibility to bring up fertility issues during cancer care (Duffy, et al., 2012) and 40% indicated that cancer patients should bring up the fertility topic themselves if they wanted to get information (Ghorbani et al., 2011). In contrast, oncologists with favorable attitudes towards FP were nearly twice as likely to discuss fertility with patients, as opposed to those with unfavorable attitudes (Quinn et al., 2009). Oncologists may deliberately refrain from initiating fertility discussions due to their own value judgments of a patient's personal circumstances. These assumptions could hinder equity of access to FP services.
2.5.3 Having an oncologist-initiated fertility discussion

We found that the levels of patient fertility concern were irrelevant when the discussion was initiated by oncologists. Furthermore, none of their socio-demographic characteristics at diagnosis nor their cancer types and treatments were significant in predicting the odds of having an oncologist-initiated fertility discussion. In fact, the only significant predictor was the year since cancer diagnosis. Women who received a cancer diagnosis after 2006 had increased odds of being counselled by their oncologists without having to initiate the discussion, as opposed to women who were diagnosed between 2000 and 2006. Moreover, 42% of women diagnosed with cancer after 2006 had an oncologist-initiated fertility discussion compared to only 13% of women who had cancer between 2000 and 2006. The FP clinical guidelines were first published by the American Society of Clinical Oncology (ASCO) in 2006 and updated in 2013 (Lee et al., 2006; Loren et al., 2013). We found there has been a positive shift in practice behaviors among Canadian oncologists to initiate a fertility discussion with cancer patients routinely since the release of practice guidelines. To our knowledge, this is the first study to distinguish the differences between oncologist-initiated versus patient-initiated fertility discussions in statistical analyses.

Prior studies conducted in the UK and US found that patients’ parental status influenced the decision of 10% to 45% of surveyed oncologists in initiating fertility discussions (Adams, Hill & Watson, 2013; Forman et al., 2010). Women who were childless at diagnosis (Duffy et al., 2005; Vadaparampil et al., 2012) were more likely to receive fertility information provided by oncology care providers. In contrast to these reports, participants’ motherhood status was not found to be a significant determinant in both our bivariate and logistic regression analyses. On the other hand, we found that partnered women and those who earned above $30,000 annually were disproportionally high in the oncologist-initiated discussion group, although these characteristics did not retain significance in the logistic regression analyses.

Our findings, as in other studies, suggest that oncologists may refrain from discussing fertility issues due to their subjective judgment of their patient’s interests in receiving fertility information based on certain socio-demographic characteristics (Forman et al., 2010; Ghorbani et
al., 2011; Quinn et al., 2007; Quinn et al., 2009a). In keeping with the fundamental principle of equity for access to medical information, all young cancer patients of childbearing age should have an equal opportunity to receive fertility information to enhance the likelihood that their reproductive autonomy is protected (Nisker, 2009, 2013; Woodruff et al., 2014).

For many young female cancer patients, childbearing post-cancer treatment is a personal decision not only embedded in individual circumstance, but also influenced by their desire for motherhood. Having a fertility discussion is the only way to find out a patient's family building plan and to accurately assess their interests in pursing FP options (Letourneau et al., 2012a; Letourneau et al., 2012b; Niemasik et al., 2012). Despite a positive shift of practice behaviors with regards to the initiation of fertility discussions among Canadian oncologists since 2006 (Lee et al., 2006; Yee et al., 2012d), there remains room for further improvement in eliminating any demographic, geographic, and socioeconomic disparities for young women in having a fertility discussion with oncology health care providers (Zebrack & Katherine Walsh-Burke, 2004).

A key strength of this study is the geographically diverse sample of young cancer survivors recruited from different provinces and regions across Canada. The participants were recruited through the help of 50 cancer groups across Canada as well as the utilization of social media to reach out to cancer survivors who may not have otherwise been reached. In addition, all women in this study were in their prime years of childbearing at cancer diagnosis, and four in five had cancer treatments with known threats to fertility. Our sample includes a mixture of young women with different cancer diagnoses instead of using a specific patient group, such as breast cancer patients who are over-represented in fertility research (Duffy et al., 2005; Gorman et al., 2010; S. Lee et al., 2011; Partridge et al., 2004).

2.6 Limitations

This study has several limitations. Although nearly a quarter of respondents did not recall having a fertility discussion with their oncologist, it is possible that given the severity of having a life threatening illness and the retrospective nature of the study, some women may not recall
having a fertility discussion with their oncologist when in fact it did occur. Cross-sectional design has limitation of establishing causality of variables under investigation. There is a potential sampling bias because participants recruited from cancer organizations might be more informative. Cancer survivors who opted to participate in this study may have had more personal interests in a research topic related to fertility and motherhood, leading to greater extremes in positive or negative retrospective accounts. The majority of our survey participants were university educated Caucasians which limits the generalizability of our findings. There is a possibility of coverage error as women with low computer literacy and less English proficiency may have chosen not to complete the online survey. Nonetheless, we believe our findings provide new insight into understanding the determinants of having a fertility discussion with oncologists and what factors play a role in influencing an oncologist's decision in initiating fertility discussions without patient prompting. Further research is needed to identify discussion prompting tools (e.g. a clinical checklist) to support oncologists in bringing up the fertility topic routinely with cancer patients without letting certain patient characteristics drive the discussion. Training programs are needed to increase oncologist sensitivity to the fertility needs of young women as well as their perceived responsibility of initiating fertility discussions, as recommended by ASCO. The goals of promoting timely FP referrals as soon as a diagnosis is made is paramount in order to best serve young women’s future chances of motherhood and post-cancer treatment quality of life.
3.1 Abstract

Objectives: Little is known about the prevalence of young Canadian female cancer patients consulting a fertility specialist to discuss their fertility preservation options at the time of cancer diagnosis. This paper identifies the factors associated with female cancer patients receiving a fertility preservation consultation prior to commencing cancer treatment.

Methods: Participants were female cancer survivors who received a cancer diagnosis after the year 2000 and were between the ages of 18 and 39 at that time. They must have completed active cancer treatment by the time of the survey (2012-2013). An online survey was conducted using a 115-item questionnaire. Approximately 50 cancer groups helped promote this study by disseminating the recruitment flyers. Pearson χ², Spearman’s correlation, and logistic regression analyses were used.

Results: A total of 143 cancer survivors who had a fertility discussion with their oncologists were included in the investigation. Of these, 49 subsequently consulted with a fertility specialist. The mean age at cancer diagnosis was 29.9 years (SD=5.6). The majority of the participants were childless (n=91, 63.6%) and in a committed relationship (n=88, 61.5%) at the time of cancer diagnosis. Five factors were found to be significantly associated with cancer patients consulting with a fertility specialist to discuss their pre-cancer treatment fertility preservation options. These factors consisted of whether the women had cancer between ages of 25 and 34 (p<.05), received gonadotoxic cancer treatment with known threats to fertility (p<.01), were childless at the time of cancer diagnosis (p<.01), had a high level of fertility concern prior to commencing cancer treatment (p<.05), and were satisfied with how their oncologists handled the fertility discussions (p<.05).
Conclusions: This is the first study that has found a link between Canadian female patients’ satisfaction with how their oncologists handled the fertility discussion and subsequent consultation with a fertility specialist. Oncologists are key knowledge brokers and gate keepers to fertility preservation services for young female cancer patients. The proactive approach of oncologists in the provision of fertility preservation resources, including the making of timely fertility preservation referrals, may enhance patient satisfaction in the quality of cancer care. Effective training programs are needed to equip oncologists with strategies to make fertility discussions an integral part of cancer care for young women so as to facilitate timely referrals to fertility experts.
3.2 Introduction

Many more young women today survive cancer due to earlier detection and better cancer treatments developed through advances in modern technology (Canadian Cancer Society, 2014). Unfortunately, cancer therapies involving alkylating agents are gonadotoxic to reproductive functions. Premenopausal women are at risk of developing premature ovarian failure as a late side effect of cancer treatment (Practice Committee of ASRM, 2013). Reproductive loss due to cancer therapies has been identified as a prominent concern for young women who have not yet completed their family at the time of cancer diagnosis (Kondapalli et al., 2014; Penrose et al., 2012; Reh et al., 2011; Wenzel et al., 2005). A body of research has shown that treatment-induced infertility can compromise the long-term quality of life and psychological well-being of young women who have survived cancer but are unable to pursue their plans for motherhood (Gorman et al., 2012; Sobota & Ozakinci, 2014; Tschudin & Bitzer, 2009; Zebrack et al., 2004).

Improved ovarian stimulation protocols and advances in cryopreservation techniques have greatly increased the options for cancer patients who wish to preserve fertility. Clinical practice guidelines issued by the American Society of Clinical Oncology (ASCO) outline the clinical responsibilities of oncologists in initiating fertility preservation (FP) discussion with young cancer patients and referring concerned individuals to fertility preservation consultations (FPC) (Lee et al., 2006; Loren et al., 2013). Since the options for young women to preserve fertility diminish drastically after the initiation of chemotherapy, early fertility discussions as soon as a cancer diagnosis is confirmed and subsequent timely FP referrals are essential for better FP outcomes (Loren et al., 2013).

Studies found that cancer patients who were counselled by their oncologists about the possible treatment-induced fertility risks had less post-treatment regret and better life satisfaction compared with those who did not have such a discussion (Kondapalli et al., 2014; Niemasik et al., 2012). Moreover, those who additionally consulted a fertility specialist for FPC had even lower post-treatment regret, higher satisfaction with life, and a better quality of life compared with women who did not have a consultation (Letourneau et al., 2012a; Reh et al., 2011). Despite these psychological benefits, numerous studies found that the percentages of women being referred to
see a fertility specialist for pre-cancer treatment FPC remain low as only 5-24% following a fertility discussion with their oncologists (Bastings, Baysal, Beerendonk, Braat, & Nelen, 2014a; Geue et al., 2014; Goodman, Balthazar, Kim, & Mersereau, 2012; Letourneau et al., 2012a; Letourneau et al., 2012b; Niemasik et al., 2012; Partridge et al., 2004). This suggests that many young patients are unable to utilize FP services due to the lack of awareness of their FP options.

To date, there is a dearth of research examining the prevalence of young Canadian female cancer patients consulting a fertility specialist to discuss their FP options prior to commencing cancer treatment. Available Canadian FP data were primarily collected by fertility centers where cancer patients had already been referred by their oncologists for a FPC (Hill et al., 2012; Yee et al., 2012a). The barriers encountered by young Canadian female cancer patients in accessing FP services at the time of diagnosis are not well understood. However, we do know that the majority of fertility centers in Canada reported low utilization of FP services by female cancer patients (Yee et al., 2012b). In a Canadian survey, about 45% of the oncologists did not know where to refer female patients for FPC and 70% rarely made FPC referrals for their female cancer patients (Yee et al., 2012d).

This paper examines two research questions. First, we ask cancer patients about the quality of the fertility discussion they had with their oncologists. Second, we identify the characteristics of cancer patients who only had a fertility discussion with their oncologist in comparison to those who also consulted a fertility specialist subsequently. Characteristics examined include cancer patient socio-demographic characteristics, cancer profiles, and the quality of the fertility discussion with their oncologists. This paper forms part of a larger study exploring participant experiences of how their fertility concerns were addressed by their oncologists at the time of receiving a cancer diagnosis, as well as their views of using assisted reproductive technologies to preserve fertility.
3.3 Methods

3.3.1 Study design

Eligible participants were women who were diagnosed with cancer after the year 2000, and were between the ages of 18 and 39 at that time. By the time of the survey, they had to have completed active cancer treatment such as chemotherapy, stem cell transplantation, or radiation. This study was approved by the University of Toronto’s Office of Research Ethics. About 50 cancer groups across Canada helped distribute the study's flyers. Social media and advertising websites were also used to reach out to female cancer survivors. Respondents were offered participation in a monthly draw to win one of the five $20 gift cards. During the 10-month study period from September 2012 to June 2013, 188 completed surveys were collected. For the purpose of this paper, 45 women who did not have a fertility discussion with any oncologist at the time of cancer diagnosis were excluded from analysis. A subset of 143 participants was used for investigation.

3.3.2 Measures

The survey was comprised of 115 questions, including some open-ended questions which allowed participants to provide detailed comments. Two independent experts in survey design and one expert in fertility preservation were consulted during the process of survey construction. Nine young female cancer survivors recruited from two cancer groups pilot-tested the online survey for content validity and readability. Minor revisions were made based on their feedback with regards to formatting, structure, clarity of questions, and inclusiveness of options in multiple choice questions. Four of them completed the revised survey two weeks afterward.

Variables used for analyses in this paper were: 1) **Socio-demographic characteristics at the time of cancer diagnosis** including age, ethnicity, residence, education, income, motherhood status, relationship status, and childbearing plan post cancer treatment; 2) **Cancer profiles** including years since cancer diagnosis, cancer type, type of cancer treatment, and level of fertility concern at diagnosis; 3) **Fertility discussion** items included who initiated the discussion, the level of satisfaction with discussion, and whether a FP referral was made.
3.3.3 Data analysis

Data analyses were conducted using the Statistical Package for the Social Sciences (SPSS) version 22.0. Participants were divided into two groups for analyses. Women who only had a fertility discussion with their oncologists were placed in the Fertility Discussion (FD) Group; those who saw a fertility specialist in addition following the discussion were placed in the Fertility Preservation Consultation (FPC) Group. The 5-point Likert scale satisfaction variable was collapsed into a dichotomous variable of ‘satisfied’ (i.e. ‘very satisfied’, ‘quite satisfied’) and ‘dissatisfied or neutral’ (i.e. ‘very dissatisfied’, ‘quite dissatisfied’, ‘neutral’). The 5-point Likert scale fertility concern variable was collapsed into a three-point variable of ‘low concern’ (i.e. ‘not concerned at all’, ‘not quite concerned’), ‘medium concern’ (i.e. ‘somewhat concerned’), and ‘high concern’ (i.e. ‘quite concerned’ and ‘very concerned’).

Pearson $\chi^2$ was used to examine the bivariate relationships of variables. Logistic regression analysis was conducted to examine factors associated with the receipt of pre-cancer treatment FPC (yes/no). A total of 13 variables were entered into 4 blocks: socio-demographic characteristics at cancer diagnosis in Block 1, cancer profiles in Block 2, fertility concern at the time of cancer diagnosis in Block 3, and participants’ perceived quality of fertility discussion with their oncologists in Block 4. The Hosmer and Lemeshow’s goodness-of-fit test in each block was checked to ensure the estimates fit the data at an acceptable level ($p>.05$). A 95% confidence interval (CI) was generated for odds ratios (OR).

Many participants wrote comments in the open-ended questions. The materials provided nuanced information to enhance our understanding of patients’ experiences of fertility discussion with their oncologists, and their perspectives about consulting a fertility specialist for FP options prior to commencing cancer treatment. Written comments were first grouped under each individual open-ended question. Thematic analysis using topics informed by the psycho-social literature on FP was conducted (Charmaz, 2006; Strauss & Corbin, 1998) to gain a more detailed understanding of participants’ evaluation of the fertility discussion with their oncologists and their FPC experiences. Extracts from the qualitative comments, where applicable, were cited in quotation to illustrate participants’ views in their own words.
3.4 Results

3.4.1 Fertility discussion

The socio-demographic characteristics of the 143 female cancer patients who had a fertility discussion with their oncologists are presented in Table 6. Their mean age at cancer diagnosis was 29.9 years (SD=5.6). The majority of the participants were childless (n=91, 63.6%) and in a committed relationship (n=88, 61.5%). The most common diagnosis was breast cancer (n=57, 39.9%), followed by cervical cancer (n=19, 13.3%). Eighty-one percent indicated that their cancer treatments involved stem cell transplantation, chemotherapy, or radiation therapy. One in four young women with cancer (n=49, 26%) consulted a fertility specialist to discuss their FP options. Among the 49 women who consulted a specialist, 34.7% (n=17) proceeded with cryopreservation of oocytes and/or embryos prior to commencing cancer treatment.

Bivariate analyses were conducted to compare the characteristics of participants in the FD Group and the FPC Group (n=94 versus n=49, Table 6). Of the 40 women who had one or more children at the time of cancer diagnosis in the FD Group (i.e. no consultation with a fertility specialist), only 10 indicated that they had completed their family. Of the 12 women who had one or more children at cancer diagnosis in the FPC Group, only 1 indicated that they had no intention to have more children at that time. Compared with the women in the FD Group, significantly more women in the FPC Group had breast cancer (51% versus 34%, p<.05), received a diagnosis in the past 3 years before survey completion (73.5% versus 50%, p<.05), had cancer treatments with known threats to fertility (91.8% versus 75.5%, p<.05), and at the time of cancer diagnosis, were between 25 and 29 (36.7% versus 20.2%, p<.05), earned above $30,000 annually (81.6% versus 64.9%, p<.05), were childless (75.5% versus 57.4%, p<.05), and had a high level of fertility concern (79.6% versus 66%, p=.05).
Table 6: Characteristics and bivariate analyses of 143 participants who had a fertility discussion with their oncologists (n=143, 94 versus 49)

<table>
<thead>
<tr>
<th>Socio-demographics at diagnosis</th>
<th>All n=143 (%)</th>
<th>Fertility Discussion Group n=94 (%)</th>
<th>Fertility Preservation Consultation Group n=49 (%)</th>
<th>p-value of the $\chi^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td>.01*</td>
</tr>
<tr>
<td>Between 18 and 24</td>
<td>28 (19.6%)</td>
<td>24 (25.5%)</td>
<td>4 (8.2%)</td>
<td></td>
</tr>
<tr>
<td>Between 25 and 29</td>
<td>37 (25.9%)</td>
<td>19 (20.2%)</td>
<td>18 (36.7%)</td>
<td></td>
</tr>
<tr>
<td>Between 30 and 34</td>
<td>42 (29.4%)</td>
<td>24 (25.5%)</td>
<td>18 (36.7%)</td>
<td></td>
</tr>
<tr>
<td>Between 35 and 39</td>
<td>36 (25.2%)</td>
<td>27 (28.7%)</td>
<td>9 (18.4%)</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>143 (100%)</td>
<td>94 (100%)</td>
<td>49 (100%)</td>
<td></td>
</tr>
</tbody>
</table>

| **Ethnicity**                   |               |                                    |                                               | .54                      |
| White                           | 125 (87.4%)   | 81 (86.2%)                          | 44 (89.8%)                                    |                          |
| Non-white                       | 18 (12.6%)    | 13 (13.8%)                          | 5 (10.2%)                                     |                          |
| **Total**                       | 143 (100%)    | 94 (100%)                           | 49 (100%)                                     |                          |

| **Residence**                   |               |                                    |                                               | .35                      |
| Metro or urban city             | 104 (72.7%)   | 66 (70.2%)                          | 38 (77.6%)                                    |                          |
| Major town or rural area        | 39 (27.3%)    | 28 (29.8%)                          | 11 (22.4%)                                    |                          |
| **Total**                       | 143 (100%)    | 94 (100%)                           | 49 (100%)                                     |                          |

| **Highest education**           |               |                                    |                                               | .68                      |
| No university degree            | 47 (32.9%)    | 32 (34%)                            | 15 (30.6%)                                    |                          |
| University degree               | 96 (67.1%)    | 62 (66%)                            | 34 (69.4%)                                    |                          |
| **Total**                       | 143 (100%)    | 94 (100%)                           | 49 (100%)                                     |                          |

| **Income**                      |               |                                    |                                               | .04*                     |
| $\leq \$30,000                  | 42 (29.4%)    | 33 (35.1%)                          | 9 (18.4%)                                     |                          |
| $> \$30,000                    | 101 (70.6%)   | 61 (64.9%)                          | 40 (81.6%)                                    |                          |
| **Total**                       | 143 (100%)    | 94 (100%)                           | 49 (100%)                                     |                          |

| **Had a child**                 |               |                                    |                                               | .03*                     |
| Yes                             | 52 (36.4%)    | 40 (42.6%)                          | 12 (24.5%)                                    |                          |
| No                              | 91 (63.6%)    | 54 (57.4%)                          | 37 (75.5%)                                    |                          |
| **Total**                       | 143 (100%)    | 94 (100%)                           | 49 (100%)                                     |                          |

| **Had a partner**               |               |                                    |                                               | .30                      |
| Yes                             | 88 (61.5%)    | 55 (58.5%)                          | 33 (67.3%)                                    |                          |
| No                              | 55 (38.5%)    | 39 (41.5%)                          | 16 (32.7%)                                    |                          |
| **Total**                       | 143 (100%)    | 94 (100%)                           | 49 (100%)                                     |                          |

| **Cancer profiles**             |               |                                    |                                               | .02*                     |
| **Years since diagnosis**       |               |                                    |                                               |                          |
| $\leq$ 3 years                  | 83 (58%)      | 47 (50%)                            | 36 (73.5%)                                    |                          |
| 4-6 years                       | 38 (26.6%)    | 29 (30.9%)                          | 9 (18.4%)                                     |                          |
| $\geq$ 7 years                  | 22 (15.4%)    | 18 (19.1%)                          | 4 (8.2%)                                      |                          |
| **Total**                       | 143 (100%)    | 94 (100%)                           | 49 (100%)                                     |                          |

<p>| <strong>Breast cancer</strong>               |               |                                    |                                               | .049*                    |
| Yes                             | 57 (39.9%)    | 32 (34%)                            | 25 (51%)                                      |                          |</p>
<table>
<thead>
<tr>
<th>Cancer treatment types</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemo, radiation or stem cell</td>
<td>116 (81.1%)</td>
<td>71 (75.5%)</td>
<td>45 (91.8%)</td>
</tr>
<tr>
<td>Surgery or others</td>
<td>27 (18.9%)</td>
<td>23 (24.5%)</td>
<td>4 (8.2%)</td>
</tr>
<tr>
<td>Total</td>
<td>143 (100%)</td>
<td>94 (100%)</td>
<td>49 (100%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Fertility concern at diagnosis</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Low (1, 2)</td>
<td>31 (21.7%)</td>
<td>26 (27.7%)</td>
<td>5 (10.2%)</td>
</tr>
<tr>
<td>Medium (3)</td>
<td>11 (7.7%)</td>
<td>6 (6.4%)</td>
<td>5 (10.2%)</td>
</tr>
<tr>
<td>High (4 to 5)</td>
<td>101 (70.6%)</td>
<td>62 (66%)</td>
<td>39 (79.6%)</td>
</tr>
<tr>
<td>Total</td>
<td>143 (100%)</td>
<td>94 (100%)</td>
<td>49 (100%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Perceived quality of fertility discussion with oncologists</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Who initiated the fertility discussion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient-initiated</td>
<td>72 (50.3%)</td>
<td>46 (48.9%)</td>
<td>26 (53.1%)</td>
</tr>
<tr>
<td>Oncologist-initiated</td>
<td>71 (49.7%)</td>
<td>48 (51.1%)</td>
<td>23 (46.9%)</td>
</tr>
<tr>
<td>Total</td>
<td>143 (100%)</td>
<td>94 (100%)</td>
<td>49 (100%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Levels of satisfaction of fertility discussion with oncologists</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Dissatisfied or neutral</td>
<td>80 (55.9%)</td>
<td>56 (59.6%)</td>
<td>24 (49%)</td>
</tr>
<tr>
<td>Satisfied</td>
<td>63 (44.1%)</td>
<td>38 (40.4%)</td>
<td>25 (51%)</td>
</tr>
<tr>
<td>Total</td>
<td>143 (100%)</td>
<td>94 (100%)</td>
<td>49 (100%)</td>
</tr>
</tbody>
</table>

Participants were asked to report the number of oncologists involved in their cancer care. Nearly a quarter (n=34, 23.8%) received care from one oncologist only, the remaining received care from two oncologists (n=62, 43.3%), three oncologists (n=38, 26.6%), and four oncologists (n=9, 6.3%). Medical oncologists were involved in the fertility discussions of 97 cases (67.8%), gynecologic oncologists in 29 cases (20.3%), surgical oncologists in 28 cases (19.6%), radiation oncologists in 23 cases (16.1%), endocrinologists in 3 cases (2.1%), and hematologists in 2 cases (1.4%). Three quarters of the cancer patients (n=108, 75.5%) had fertility discussions with one oncologist only. The remaining had fertility discussion with two oncologists (n=25, 17.5%) and
three oncologists (n=10, 7%). One participant wrote about her positive experience of having more than one oncologist discussing fertility matters with her since the beginning of her cancer care:

“The conversation actually started with my surgeon. She said my oncologist would be able to provide more information. It was one of the things he talked about in our first meeting.” (Diagnosed at age 30, single, no children)

Of the 71 participants (49.7%) who indicated that their fertility discussions were initiated by their oncologists, 45 were childless women and 26 had one or more biological children. Among those women who were a mother already at diagnosis, 11 had one child, 13 had two children, and 2 had three or more children. The words of one young woman illustrate the value felt by many of such proactive stances on the part of oncologists:

“They brought it up, said I might not be able to have children, I said I wasn't concerned if I couldn't have children. They pressed me to make sure I really wasn't concerned and that I knew all the information anyway in case it becomes a concern in the future.” (Diagnosed at age 24, partnered, no children)

On the other hand, half of the participants had to initiate the discussion by asking their oncologist for fertility information (n=72, 50.3%). Among them, 46 were childless women, 22 were mothers of one child, and 4 were mothers of two children.

“I was shocked that the issue wasn't brought up by my oncologist, and that the only reason the topic was addressed was because I asked. At the time, I appreciated his candor, but in retrospect, I'm surprised he dismissed the concern in favor of starting treatment promptly.” (Diagnosed at age 28, partnered, one child)
Table 7 presents the participant levels of fertility concern and their satisfaction with the quality of the fertility discussion they had with their oncologists. Significantly more participants whose fertility discussions were self-initiated showed a high level of fertility concern at diagnosis compared with those whose fertility discussions were oncologist-initiated (86.1% versus 54.9%, p<.001). In contrast, significantly more women whose fertility discussions were initiated by their oncologists showed a low level of fertility concern at diagnosis compared with those who had to ask their oncologists for fertility information (35.2% versus 8.3%, p<.001).

Table 7: Participants’ satisfaction of fertility discussion and their levels of fertility concern by the initiation of fertility discussion (n=143)

<table>
<thead>
<tr>
<th></th>
<th>Patient-Initiated Fertility Discussion (n=72)</th>
<th>Oncologist-Initiated Fertility Discussion (n=71)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fertility concern at diagnosis</strong> a</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low (1, 2)</td>
<td>6 (8.3%)</td>
<td>25 (35.2%)</td>
<td>31 (21.7%)</td>
</tr>
<tr>
<td>Medium (3)</td>
<td>4 (5.6%)</td>
<td>7 (9.9%)</td>
<td>11 (7.7%)</td>
</tr>
<tr>
<td>High (4 to 5)</td>
<td>62 (86.1%)</td>
<td>39 (54.9%)</td>
<td>101 (70.6%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>72 (100%)</td>
<td>71 (100%)</td>
<td>143 (100%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Satisfaction of fertility discussion with oncologists</strong> b</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dissatisfied or neutral</td>
<td>54 (75%)</td>
<td>26 (36.6%)</td>
<td>80 (55.9%)</td>
</tr>
<tr>
<td>Satisfied</td>
<td>18 (25%)</td>
<td>45 (63.4%)</td>
<td>63 (44.1%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>72 (100%)</td>
<td>71 (100%)</td>
<td>143 (100%)</td>
</tr>
</tbody>
</table>

a Pearson χ² (2, n=143) = 17.70, p<.001, φ=.35  
b Pearson χ² (2, n=143) = 21.22, p<.001, φ=.39

3.4.2 Satisfaction of fertility discussion with oncologists

Overall, less than half of the participants (n=63, 44.1%) were satisfied with how their oncologists handled the fertility discussions, whereas one-third (n=48, 33.6%) were dissatisfied, and the remaining (n=32, 22.4%) were neutral (Table 7). Of the 72 women whose fertility discussions were self-initiated, only 1 in 4 (25%) was satisfied with how their oncologists handled their fertility discussion. One woman reports that “had I not asked I would have had no idea of the risks of infertility after chemo” (Diagnosed at age 20, single, no children). Of the 71 women whose
fertility discussions were initiated by their oncologists, nearly 2 in 3 (63.4%) were satisfied with how their oncologists handled their fertility discussion. Bivariate analysis found that whether or not the participants were satisfied with how their oncologists handled the fertility discussions was significantly associated with who initiated the fertility discussion ($p<.001$).

Review of the written comments soliciting participant experience of the fertility discussion they had with their oncologists reveals that participant satisfaction was not only related to oncologist competencies in handling the discussion, but also oncologist willingness in taking their fertility concerns seriously and sensitively. One woman reports that “My oncologist was very empathetic to my wishes to have children. He was quite knowledgeable and gave me some helpful literature. He answered all of my questions” (Diagnosed at age 27, partnered, no children).

However, a significant number of women did not find their fertility concerns were addressed sensitively by their oncologists. Some commented that even when fertility was discussed during cancer care, “it was an after-thought” for their oncologists and “wasn't much of a conversation”. Others commented that their fertility discussions were “only a 5-minute conversation” and “a pretty minimal conversation” that their oncologists “just mentioned casually and not discussed [fertility] again”. A few felt their oncologists brushed off their fertility concerns and undermined their fertility needs:

“I valued his opinion with regards to how soon we needed to move with the therapy and I feel as a result he basically gave the distinct impression that fertility ought to be the LEAST of my concerns during that time.” (Capitals in original) (Diagnosed at age 33, partnered, no children)

Participants were also more likely to be dissatisfied when the discussions were unclear:

“I wasn't able to get any answers from any of my specialists [oncologists]. The answer given was, ‘I cannot say either way if your
body will be able to reproduce, it's more just trial and error. You are young, you always hear about miracles happening.” (Diagnosed at age 19, single, no children)

3.4.3 Odds of receiving a fertility preservation consultation (n=143, 94 versus 49)

The logistic regression in Table 8 identifies five significant factors associated with receiving a consultation with a fertility specialist prior to the initiation of cancer treatment. The odds of consulting with a fertility specialist were higher among women who were diagnosed with cancer between ages 25 and 34 ($p<.05$), who were childless at cancer diagnosis ($p<.01$), with a high level of fertility concern at diagnosis ($p<.05$), who were satisfied with how their oncologists handled the fertility discussion ($p<.05$), and who had cancer treatment involving chemotherapy, radiation therapy, or stem cell transplantation ($p<.01$). The final model predicts 38.3% of the variance in consulting with a fertility specialist, with the main contributor being socio-demographic characteristics in Model 1 (19.6%). When the patient cancer profiles were added to the analysis (Model 2), an additional 9.6% of the variance was explained. The levels of fertility concern and satisfaction of the fertility discussion with their oncologists contributed an additional 5.1% and 4% of the variance, respectively (Model 3 and Model 4).

After taking account of other variables in the model, childless women were four times more likely to consult a fertility specialist than women who had a child already at diagnosis. The odds were five to six times more for women who received a diagnosis in the age ranges of 25 to 34, compared with those who were under age 25 at diagnosis. Women who received chemotherapy, radiation, or stem cell transplantation were seven times more likely to consult a fertility specialist than others who only had surgery or other cancer treatments. Women who had a high level of fertility concern at diagnosis were also four times more likely to receive a FPC compared with women who had a low fertility concern. Finally, women who were satisfied with how their oncologists handled the fertility discussion were three times more likely to see a fertility specialist for FPC than those who were either dissatisfied or neutral with the fertility discussion. Whether the fertility discussion was initiated by cancer patients or their oncologists was not found to be a significant determinant in the receipt of FPC.
Table 8: Logistic regression analysis of factors associated with receiving a fertility preservation consultation (n=143, 94 versus 49)

<table>
<thead>
<tr>
<th></th>
<th>Model 1 OR* (95% CI)*</th>
<th>Model 2 OR (95% CI)</th>
<th>Model 3 OR (95% CI)</th>
<th>Model 4 OR (95% CI)</th>
</tr>
</thead>
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<tr>
<td><strong>BLOCK 1: Socio-demographics at diagnosis</strong>^d</td>
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<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Between 18 and 24</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Between 25 and 29</td>
<td>5.57 (1.31 to 23.61)</td>
<td>5.90 (1.21 to 28.84)</td>
<td>5.78 (1.17 to 28.63)</td>
<td>5.3 (1.04 to 27.04)</td>
</tr>
<tr>
<td>Between 30 and 34</td>
<td>6.28 (1.36 to 29.00)</td>
<td>5.95 (1.11 to 32.00)</td>
<td>5.78 (1.08 to 31.05)</td>
<td>6.55 (1.17 to 36.81)</td>
</tr>
<tr>
<td>Between 35 and 39</td>
<td>2.79 (.56 to 14.00)</td>
<td>2.42 (.41 to 14.42)</td>
<td>3.12 (.52 to 18.81)</td>
<td>3.22 (.52 to 19.87)</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
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</tr>
<tr>
<td>White</td>
<td>1.34 (.38 to 4.65)</td>
<td>1.52 (.41 to 5.67)</td>
<td>1.50 (.40 to 5.71)</td>
<td>1.32 (.33 to 5.37)</td>
</tr>
<tr>
<td>Non-white</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
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<tr>
<td>Total</td>
<td></td>
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<tr>
<td><strong>Residence</strong></td>
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<td></td>
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</tr>
<tr>
<td>Metro or urban city</td>
<td>1.28 (.52 to 3.19)</td>
<td>1.68 (.63 to 4.47)</td>
<td>1.50 (.53 to 4.19)</td>
<td>1.32 (.45 to 3.89)</td>
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<td>Major town or rural area</td>
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<tr>
<td>Total</td>
<td></td>
<td></td>
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<tr>
<td><strong>Highest education</strong></td>
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<tr>
<td>No university degree</td>
<td>.79 (.33 to 1.88)</td>
<td>.78 (.32 to 1.95)</td>
<td>.84 (.33 to 2.13)</td>
<td>.77 (.30 to 2.01)</td>
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<td>University degree</td>
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<tr>
<td>Total</td>
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<tr>
<td><strong>Income</strong></td>
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<tr>
<td>&lt;= $30,000</td>
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<tr>
<td>&gt; $30,000</td>
<td>1.28 (.42 to 3.92)</td>
<td>.98 (.27 to 3.58)</td>
<td>1.19 (.31 to 4.52)</td>
<td>1.86 (.45 to 7.76)</td>
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<tr>
<td><strong>Had a child</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
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<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>No</td>
<td>3.63 (1.41 to 9.36)</td>
<td>3.28 (1.22 to 8.83)</td>
<td>3.31 (1.20 to 9.16)</td>
<td>4.28 (1.45 to 12.62)</td>
</tr>
<tr>
<td>Total</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Had a partner</strong></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Yes</td>
<td>1.50 (.61 to 3.66)</td>
<td>1.28 (.48 to 3.37)</td>
<td>1.25 (.44 to 3.54)</td>
<td>1.00 (.33 to 3.02)</td>
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<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
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<tr>
<td>Total</td>
<td></td>
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<tr>
<td><strong>BLOCK 2: Cancer profiles</strong>^e</td>
<td></td>
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<td></td>
</tr>
<tr>
<td><strong>Years since diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;= 3 years</td>
<td>---</td>
<td>2.32 (.59 to 9.19)</td>
<td>2.61 (.62 to 10.96)</td>
<td>2.16 (.49 to 9.50)</td>
</tr>
<tr>
<td>4-6 years</td>
<td>---</td>
<td>1.27 (.27 to 6.05)</td>
<td>1.83 (.34 to 9.89)</td>
<td>1.56 (.27 to 8.87)</td>
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<tr>
<td>&gt;= 7 years</td>
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<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
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<tr>
<td><strong>Breast cancer</strong></td>
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<tr>
<td>Yes</td>
<td>---</td>
<td>2.06 (.85 to 5.0)</td>
<td>2.01 (.81 to 5.0)</td>
<td>1.71 (.68 to 4.34)</td>
</tr>
<tr>
<td>No</td>
<td>---</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
</tbody>
</table>
Of the 92 women who were not referred to see a fertility specialist, 40 (43.5%) would have ‘definitely’ or ‘probably’ chosen to be referred if they were given a chance, 25 (27.2%) were uncertain, whereas 27 (29.3%) would have ‘probably’ or ‘definitely’ chosen not to be referred. Some patients did not have a FP referral because of oncologist judgment on their fertility needs at the time of cancer diagnosis as they perceived that their oncologists “felt unless I wanted to have kids right now, it wasn't necessary” (Diagnosed at age 19, single, no children).

A few participants who were not offered a chance to see a fertility specialist wondered why their oncologists didn't make a FPC referral when technologies were available to preserve fertility.

<table>
<thead>
<tr>
<th>Cancer treatment types</th>
<th>3.59^c (1.03 to 12.55)</th>
<th>4.46^c (1.24 to 16.11)</th>
<th>7.04^b (1.77 to 28)</th>
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<tbody>
<tr>
<td>Surgery or others</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>BLOCK 3: Fertility concern at diagnosis^f</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low (1, 2)</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
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<tr>
<td>Medium (3)</td>
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<tr>
<td></td>
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<tr>
<td>High (4 to 5)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>BLOCK 4: Perceived quality of fertility discussion with oncologists^g</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initiation of discussion</td>
</tr>
<tr>
<td>Patient-initiated</td>
</tr>
<tr>
<td>Oncologist-initiated</td>
</tr>
<tr>
<td>Total</td>
</tr>
<tr>
<td>Satisfaction of discussion</td>
</tr>
<tr>
<td>Dissatisfied or neutral</td>
</tr>
<tr>
<td>Satisfied</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

| Total |                        |                        |                        |

^a OR: odds ratio; CI: Confidence interval
^b p<.01
^c p<.05
^d Nagelkerke R² for Block 1=.196, p=<.01
^e Change in Nagelkerke R² associated with Block 2 =.096, p<.05
^f Change in Nagelkerke R² associated with Block 3=.051, p<.05
^g Change in Nagelkerke R² associated with Block 4=.040, p<.05
Full model Nagelkerke R²=.383, p<.001
A woman questions, “If that [fertility preservation] was a resource at my disposal, why wouldn't a doctor mention it?” (Diagnosed at age 28, single, no children). Another woman shared her dissatisfaction in a written comment:

“When asked, my oncologist answered that there was a risk after treatment that fertility might be an issue, but he never provided any options in terms of preserving my eggs. I clearly would have wanted my oncologist to explain about options for egg preservation and to refer me to a fertility specialist. I felt that my concerns about fertility were not addressed. Ideally, I think the medical team should discuss fertility issues with the patient soon after the cancer diagnosis is announced.” (Diagnosed at age 32, single, no children)

Another participant who wanted to receive FPC but was told that pursuing FP would put her survival chance at risk:

“It was stressed to me that the option would be pointless and put my chance of survival at high risk. I don’t know how fast referrals can be made, told that egg freezing not very successful, did not have a ‘sperm donor’ at the time as I was recently separated and not dating.” (Diagnosed at age 33, separated, no children)

On the other hand, one woman applauded her oncologist’s respectful and supportive attitude of suggesting a FPC:

“My oncologist was very insistent that I should think seriously about going to the fertility clinic before we start chemotherapy, even though we both equally agreed that we couldn’t delay treatment. She was respectful, extremely supportive and gave me all the phone numbers and information if I decided to give it a try. She explained
the side-effects of chemo and my statistical risk of being infertile.”
(Diagnosed at age 37, partnered, no children)

The importance for oncologists to provide patients with adequate FP information was well encapsulated in a written comment:

“It is so important to educate the medical oncology team about providing cancer patients with all of the fertility options. They need to understand that fertility/infertility issues that are cancer-related have a huge impact on the cancer patients as well on their spouse/partner. Fertility options should be part of the process when receiving one’s pathology report. Patients should be provided with extensive information and given enough time if they choose to go through egg/embryo preservation.” (Diagnosed at age 39, partnered, no children)

3.5 Discussions
3.5.1 Patient-related determinants

Our findings contribute to the limited body of research examining the trends and disparities of the receipt of FP services among Canadian female cancer patients. In this study, we found that only one-third of the participants who had a fertility discussion with their oncologists saw a fertility specialist subsequently. Of the two-thirds who did not receive a FPC, 44% indicated that they would like to have seen a fertility specialist regarding their FP options if they were given a chance, a finding that is consistent with previous research (Gorman et al., 2011; Gorman et al., 2012; S. Lee et al., 2011; Penrose et al., 2012).

Prior research also suggest that many young women have a strong interest in receiving FP information at the time of cancer diagnosis (Gorman et al., 2012; Peate et al., 2009); most have favorable attitudes towards undergoing FP procedures to preserve fertility (Garvelink, 2013;
Tschudin et al., 2010). Speaking to a fertility specialist on the efficacy, benefits, risks, success rates, and costs associated with cryopreservation procedures is the preferred way of obtaining personalized FP information in order to make an informed medical decision (Peate et al., 2009; Thewes et al., 2005). By not making timely FP referrals, young women with cancer are denied their choice for informed FP decisions, potentially leading to future regret and psychological distress (Connell et al., 2006; Hershberger et al., 2013; R. J. Lee et al., 2011).

Studies have suggested that certain socio-demographic characteristics, patient factors, and cancer profiles are associated with the increased likelihood of FP referrals (Goodman et al., 2012; S. Lee et al., 2011). Cancer patients who were younger (Goodman et al., 2012; Letourneau et al., 2012b), heterosexual (Letourneau et al., 2012b), childless (Goodman et al., 2012; Letourneau et al., 2012b), white (Goodman et al., 2012; Letourneau et al., 2012b), college educated (Letourneau et al., 2012b), and had breast cancer (Bastings et al., 2014a; Goodman et al., 2012) were more likely to receive a pre-cancer treatment FP referral. In this study, we found that childless women who received a cancer diagnosis between the ages of 25 and 34, who had a high fertility concern at diagnosis, whose cancer treatments had known threats to fertility, and who were satisfied with how their oncologists handled the fertility discussion had higher odds of consulting a fertility specialist prior to their cancer treatment. To our knowledge, this is the first study that has found a link between the quality of the oncologist-patient fertility discussions and the subsequent receipt of FPC.

The birth rate among women in their twenties has declined steadily in the past few decades in all developed countries (Matthews & Hamilton, 2009). Moreover, the average age of having a first born child increased from 21.4 years in 1970 to 25.8 years in 2012 for American women. The increase in the average age was comparable among Canadian women, from 23.7 years in 1970 to 28 years in 2012 (Martin, Hamilton & Osterman et al., 2012). In this study, the mean age at cancer diagnosis of our participants was 30; 62% of the participants were in a committed relationship and 64% were childless at the time of diagnosis. Of the 52 (36%) participants who already had one or more children at diagnosis, only 11 indicated that they did not plan to have more children post...
cancer treatment. This suggests that, at the time of their cancer diagnosis, most of our participants had unfulfilled plans to have one or more children.

In this study, among the 72 women who initiated the fertility discussion with their oncologists, 86% were very concerned about their fertility at cancer diagnosis. Of the remaining 71 participants whose fertility discussions were initiated by their oncologists, 55% reported a high degree of fertility concern. In addition, those who were very concerned about their fertility at diagnosis were four times more likely to receive a FPC compared with women who had a low fertility concern. It is quite likely that patient levels of fertility concern are highly correlated with the woman's desire for children at diagnosis (Partridge et al., 2004). However, it is important to recognize that the levels of fertility concern are also dependent on life circumstances, such as relationship status. Women who were single at diagnosis may establish a committed relationship after cancer treatment and regret the missed opportunity to preserve their reproductive chances. Also, the levels of fertility concern at diagnosis may be overshadowed by the cancer diagnosis when the main focus at the initial stage is on surviving the illness (Gorman et al., 2011).

We found that cancer patients who had at least one child already at diagnosis had lower odds of receiving a FPC compared with others who were childless. Similarly, prior studies found that cancer patients who had children already at diagnosis (Goodman et al., 2012; Niemasik et al., 2012; Yee et al., 2012a) and who were uncertain about their future childbearing plans (Duffy et al., 2005) were less likely to receive fertility information from their oncology care providers and were less likely to receive a FP referral. However, the inability to fulfill one’s original childbearing plan due to secondary infertility can be just as distressing as primary infertility among cancer survivors (Wenzel et al., 2005). Therefore all young women, regardless of their motherhood status, should have the same right of receiving a consultation concerning their FP options prior to commencing cancer treatment.

In this study, the receipt of FPC was not significantly associated with cancer patient relationship status at the time of diagnosis – a finding also supported by Letourneau and colleagues (2012b). In fact, a recent study also reported an increased trend of more single women being
referred for pre-cancer treatment FPC (Bastings et al., 2014a). Advances in freezing technologies in the past decade have greatly improved the efficacy of oocyte cryopreservation procedures with promising clinical outcomes. The American Society of Reproductive Medicine has also lifted the experimental label of oocyte cryopreservation (Society for Assisted Reproductive Technology & Practice Committees of ASRM, 2013), making oocyte freezing a viable FP option for cancer patients who are single and do not wish to use donor sperm for embryo cryopreservation.

Our data also show that significantly more breast cancer patients were in the FPC Group than in the FD Group. Prior studies have also found that breast cancer patients were more likely to receive FPC than women with other cancer types (Goodman et al., 2012; Mersereau et al., 2013). Breast cancer is the most common malignancy among premenopausal women in reproductive ages (Canadian Cancer Society, 2014). It is also the most commonly targeted cancer group in FP studies (Balthazar et al., 2012; Meneses, McNees, Azuero, & Jukkala, 2010; Partridge et al., 2004; Peate et al., 2009; Thewes et al., 2003). Perhaps oncologists who specialize in treating gynecologic cancers, such as breast, cervical, and ovarian cancers, are more attentive to the fertility needs of young women; they may be more accustomed to making FP referrals due to their case volume (Balthazar et al., 2012). Despite that, we did not find having a breast cancer diagnosis was a significant predictor in the multivariate logistic regression when adjustments made for other factors.

Numerous studies conducted in the U.S. found that patient socioeconomic status is influential in the oncologist decision to refer patients to a fertility specialist due to the costs of FPC and FP procedures (Adams et al., 2013; Goodman et al., 2012; Kim et al., 2013; Mersereau & Sandbulte, 2013). In contrast, we found that earning an annual income above $30,000 was not a significant predictor in the receipt of FPC for young cancer patients. However, the income information may be somewhat misleading because our survey asked about individual income rather than household income while 62% of participants were in a committed relationship at the time of cancer diagnosis. Our findings could also be due to the fact that our sample included respondents from the province of Quebec where government funding for FP services has been
available since August 2010. However, a recent study conducted in the Netherlands – where FP services are state-funded – reported a low referral rate, with only 9.8% of young female cancer patients being referred for pre-cancer treatment FPC even though there is no financial reason for oncologists to refrain from FP referrals (Bastings et al., 2014a).

3.5.2 Oncologist-related determinants

Studies surveying the FP practice behaviors of oncologists found discordance between awareness of regulations, self-report of referral to FPC, and actual referral behaviors. A national survey of US oncologists found that although 60% indicated an awareness of the ASCO’s FP practice guidelines, less than one quarter followed the recommendations in their clinical practice on a regular basis (Quinn et al., 2007). In another nationwide US survey, 95% of the responding oncologists reported discussing fertility with cancer patients routinely, although 61% rarely or never made a FPC referral (Forman et al., 2010). In a Netherlands study, the majority of oncology care providers indicated that they ‘often’ or ‘always’ referred their patients for FPC, but in reality less than 10% of their cancer patients received FP services (Bastings et al., 2014a). These discrepancies suggest that the actual compliance of ASCO’s recommendations may be even lower than the figures reported in the research literature.

Oncologists are key knowledge brokers and gate keepers to FP services for young cancer patients. Oncologists control what information to, or not to, discuss during medical appointments (Niemasik et al., 2012). We found that three quarters of our survey participants had fertility discussions with only one oncologist. Cancer specialists other than medical oncologists were involved in only 20% of the fertility discussions. Quite likely, more than one oncologist is involved in the care of each cancer patient, and surgical oncologists are usually the first cancer specialists in care. Studies found that gynecologic oncologists were more likely to routinely consider fertility compared with other oncologists (Forman et al., 2010); radiation and medical oncologists were also more likely to discuss the impact of cancer treatments on fertility with patients than surgical oncologists (Gwede, Vadaparampil, Hoffe, & Quinn, 2012). The likelihood of patients receiving a FP referral would increase if each cancer specialist, especially the surgical oncologist brings up the fertility discussion with cancer patients routinely (Lee, Ozkavukcu, Heytens, Moy, & Oktay, 2010).
There is a need to raise the awareness and knowledge among different cancer specialists of the latest cryopreservation methods to facilitate FP referrals.

In this study, half of the fertility discussions were initiated by the participants. This suggests that a significant portion of oncologists were inattentive to the fertility needs of their patients, and some of the fertility discussions may not have occurred if patients did not take the initiative to ask questions. Oncologists may not be well prepared to handle patient queries on fertility matters if they are not the ones to drive the discussion. Furthermore, we found that participant satisfaction of how their oncologists handled the fertility discussion was a significant determinant associated with the odds of seeing a fertility specialist. A US survey on young cancer patients found that three quarters of the fertility discussions were initiated by oncologists and 68% were satisfied with the quality of their discussion (Scanlon et al., 2012). Another UK study found that most female cancer patients were dissatisfied with how their oncology providers handled the fertility discussions because of their inability to provide FP information and resources (Yeomanson et al., 2013).

In conclusion, deficiencies in oncologist-patient communications on FP matters, including uncertainty and lack of clarity in fertility answers received from oncologists could negatively impact patient experience, confidence, and satisfaction with cancer care (Corney & Swinglehurst, 2014; S. Lee et al., 2011; Niemasik et al., 2012; Peddie et al., 2012). A proactive approach of oncologists in the provision of FP resources, including making timely FP referrals, would enhance patient satisfaction in the quality of cancer care (Bastings et al., 2014a). Effective training programs are needed to equip oncologists to make fertility discussion an integral part of cancer care for young women so as to facilitate timely referrals to fertility experts.

3.6 Limitations

This study has several limitations. Retrospective accounts of fertility discussion during cancer care may be subject to recall bias. Non-white groups were underrepresented in our sample composition, which limits the generalizability of the findings to other populations. There is a potential sampling bias because participants were recruited from cancer organizations and
therefore they may have more cancer knowledge. Furthermore, women who opted to participate in this study in response to the recruitment survey flyer may have had more personal interest in the research topic related of cancer and fertility, and if so, these personal interests may have led to greater extremes in reported satisfaction or dissatisfaction with how their oncologists handled their fertility concerns during cancer care. Nonetheless, we believe the findings from this large, national study provides new insight into the crucial role played by Canadian oncologists in making timely referrals for young cancer patients to see a fertility specialist.
CHAPTER 4
Factors associated with proceeding with fertility preservation

4.1 Abstract

Objectives: This paper examines the factors associated with female cancer patients’ decisions on proceeding with pre-cancer treatment fertility preservation after consulting a fertility specialist.

Methods: Participants were female cancer survivors who received a cancer diagnosis after the year 2000 and were between the ages of 18 and 39 at that time. They must have had completed active cancer treatment by the time of survey completion. Data were collected from September 2012 to June 2013 using a 115-item online questionnaire. A total of 188 completed surveys were collected and a subset of the 49 cancer survivors who consulted a fertility specialist prior to commencing cancer treatment was used for this investigation. Pearson $\chi^2$, Spearman’s correlation, and logistic regression were used for analyses.

Results: Seventeen participants (34.7%) cryopreserved their oocytes and/or embryos following their fertility preservation consultations. The top two preferred styles of treatment decision-making were for patients to make their own treatment decisions after seriously considering their doctor’s opinion (n=15, 30.6%), followed by making a joint decisions with their doctors (n=13, 26.5%).

Higher odds of proceeding with cryopreservation procedures were evident for patients with a high degree of fertility concern and for those who perceived their oncologists as supportive of their fertility preservation plan. For those who underwent a fertility preservation procedure, nearly two-thirds of their pre-consultation fertility discussions were initiated by oncologists and three quarters were satisfied with how their oncologists handled the discussions. Participants who found their oncologists supportive of their fertility preservation plan had lower decision regret regardless of whether they chose to preserve fertility or not, and they had more confidence that their decisions were based on an informed choice compared with others whose oncologists were neutral or non-supportive.
Conclusions: Oncologists play a pivotal role in supporting female cancer patients in making time-sensitive fertility preservation decisions concurrent with considerations of cancer treatment options. Cancer patients who reported being satisfied with how their oncologists handled their fertility discussions were more likely to report they were properly informed of their fertility preservation options, were satisfied with their fertility preservation decisions, and that they had little post-decision regret.
4.2 Introduction

Many life-saving cancer treatments are gonadotoxic with deleterious late side effects on ovarian functions that could impair fertility. Advances in cryopreservation technologies and improvement in ovarian stimulation protocols have increased the fertility preservation (FP) options for young cancer patients who are at risks of infertility after completing cancer treatment (Ethics Committee of ASRM, 2013; Practice Committee of ASRM, 2013). Since the American Society of Clinical Oncology (ASCO) released the oncology FP clinical practice guidelines in 2006 (Lee et al., 2006), there has been an increasing trend of more young females being referred by their oncologists for fertility preservation consultation (FPC) (Lee et al., 2010; Letourneau et al., 2012b).

Previous studies have shown that women who received pre-cancer treatment FPC were more able to cope with infertility stress and reproductive challenges during their cancer survivorship (Carter et al., 2010; Goodman et al., 2012; Quinn et al., 2009). Furthermore, those who took action to preserve fertility had less decisional regret (Letourneau et al., 2012a), fewer decisional conflicts (Kim et al., 2013; Mersereau et al., 2013), and higher life satisfaction (Mersereau et al., 2013) compared with those who chose not to proceed with FP. Despite these psychological benefits for cancer patients to preserve fertility, many survivors recalled having a substantial amount of stress and time pressure when making their FP decision (Hill et al., 2012; Mersereau et al., 2013; Peate et al., 2011; Peate et al., 2012).

Prior research has also found that cancer patients with better fertility knowledge experienced less decisional conflicts and uncertainty in their FP decision than women without such knowledge (Kim et al., 2013; Peate et al., 2011). Although consulting a fertility specialist is the most helpful way to obtain personalized medical information about FP options (Kim et al., 2013; Thewes et al., 2003), the pivotal role played by oncologists in supporting cancer patients during the FP decision-making process cannot be underestimated. Given the time-sensitive nature of FP procedures (FPP), oncologists play crucial roles as knowledge brokers in initiating fertility discussions with young women as soon as a cancer diagnosis is made, and as gatekeepers in making early FP referrals for concerned individuals to receive timely FP services (Noyes et al., 2013; Quinn et al., 2009).
Building on existing research examining the nuances of oncologist-patient communication on fertility matters and the experiences of young cancer patients in FPC, this study investigates four questions related to FP decision-making. First, we examine the factors associated with female cancer patient decisions to preserve fertility after consulting a fertility specialist of their FP options. Second, we examine participant appraisal of the quality of their FP decision in retrospect. Third, we examine if there is an association between the uptake of FP and the quality of the fertility discussions participants had with their oncologists before they were referred to see a fertility specialist. Finally, we investigate the pivotal role played by oncologists in supporting cancer patients to make a high quality FP decision. To the best of our knowledge, this is the first study examining the association of fertility discussions provided by oncologists with the subsequent uptake of FP.

4.3 Methods

4.3.1 Study design

The study was approved by the Research Ethics Board of the University of Toronto. Eligible participants were female cancer survivors who received a cancer diagnosis since the year 2000 and were aged 18-39 at that time. By the time of the survey, they had to have completed active cancer treatment such as chemotherapy, stem cell transplantation, or radiation.

Two independent experts in survey design and one expert in fertility preservation were consulted during the process of survey construction. Nine young female cancer survivors recruited from two cancer organizations\(^3\) pilot-tested the web-based survey for content validity and readability. Minor revisions were made based on their feedback with regards to formatting, structure, clarity, and inclusiveness of options in multiple choice questions. Four of them completed the revised survey two weeks afterward.

A web search was conducted to establish a contact list of cancer organizations and groups across Canada. About 50 cancer groups helped promote the study by disseminating the recruitment flyers, and posting the study’s website domain and the survey’s URL through their channels. In addition, advertising websites (i.e. Kijiji, Craigslist) and social media platforms (i.e. Facebook, Twitter) were used to reach out to potential participants. Participants were not directly rewarded for survey completion but were offered entrance into a monthly draw to win one of the five $20 gift cards. A total of 188 completed surveys were collected during the data collection period from September 2012 to June 2013. A subset of 49 cancer survivors who received a FPC following a fertility discussion with their oncologists was used for investigation. This paper forms part of a larger study exploring participant views on cancer, fertility, and motherhood. Findings related to the fertility discussions with their oncologists and the subsequent receipt of fertility preservation consultation are reported separately.

4.3.2 Measures

Data were collected using an anonymous online survey comprised of 115 questions. Open-ended questions were included to allow the participants to further elaborate their perspectives and experiences in written comments. Variables used for investigation in this paper included: a) socio-demographic characteristics and patient factors including age at cancer diagnosis, current age, ethnicity, education, income, relationship status, motherhood status, and procreation desire post cancer treatment; b) cancer profiles including year since cancer diagnosis, cancer type, cancer stage, treatment types, and degree of fertility concern; c) fertility discussion with oncologists including initiation of discussion, level of satisfaction, and perceived support from oncologists of the FP plan; and d) FP referrals including who made the referral, waiting time for FPC appointment, FP decision, levels of stress and time pressure in decision-making, and FP outcomes.

Participant preferred roles in medical decision-making were measured by the Control Preferences Scale (Degner et al., 1997). The scale has 5 items, each with a 5-point ordinal scale ranging from 1 ‘most preferred’ to 5 ‘least preferred’ to measure the degree of autonomy an individual wants to assume when making important medical decisions.
Three standardized scales focused on treatment decision-making were used to measure three different qualities of the FP decision: informed choice, satisfaction with decision, and decisional regret. The word ‘treatment’ was replaced by ‘fertility preservation’ or ‘preserve fertility’ to make the questions situation-specific to the research topic. Cronbach’s alpha was calculated to determine internal consistency:

a) *Informed Choice Subscale from the Treatment Decision Evaluation Scale* (Stalmeier et al., 2005) contains 5 items, each with a 5-point ordinal scale measuring patient confidence that their choice of treatment decision was fully informed. The summed scores range from 5 to 25, with higher scores indicating their confidence in the information they had received was fully informed. The scale has high internal reliability (α=0.85).

b) *Satisfaction with Decision Scale* (Holmes-Rovner et al., 1996) contains 6 items, each with a 5-point ordinal scale measuring the levels of satisfaction with treatment decisions. One item, ‘I expect to successfully carry out (or continue to carry out) the decision I made’, was removed because the FP choice was a one-time decision that had already been made. The summed scores range from 5 to 25, with higher scores indicating higher overall satisfaction with treatment decision. The scale has high internal reliability (α=0.95).

c) *Decisional Regret Scale* (Brehaut et al., 2003) contains 5 items, each with a 5-point ordinal scale measuring the degree of regret regarding a specific medical decision. The summed scores range from 5 to 25, with higher scores indicating more regret with the treatment decision. The scale has high internal reliability (α=0.93).

4.3.3 Data analysis

Data analyses were conducted using the Statistical Package for the Social Sciences (SPSS) version 22.0. Participants were divided into two groups for analyses. Women who consulted a fertility specialist only were classified as the FPC group; others who subsequently proceeded with FP following the consultation were classified as the FPP group.
Three variables were used to examine the quality of fertility discussion with oncologists: a) whether or not the fertility discussion was oncologist- or patient-initiated (dichotomous variable), b) the level of satisfaction with the discussion (5-point ordinal variable), and c) the level of oncologist support of FP plan (5-point ordinal variable). These two 5-point variables were further collapsed into dichotomous variables for analyses. The categories ‘very satisfied’/‘satisfied’ and ‘very supportive’/‘supportive’ were collapsed into one group; ‘neutral’/‘dissatisfied’/‘very dissatisfied’ and ‘neutral’/‘non-supportive’/‘very non-supportive’ were collapsed into another group.

Pearson \( \chi^2 \) and Spearman’s correlation were used to examine the bivariate relationships between variables. Logistic regression was used to analyze the factors associated with the odds of proceeding with FP after the FPC (yes/no). Univariate logistic regression was conducted first to evaluate the odds of uptake of FP for each variable. Multivariate logistic regression was then conducted using the variables that were significant at \( p<.20 \) in univariate analyses. The Hosmer and Lemeshow’s goodness of fit test was checked to confirm the estimates fit the data at an acceptable level (\( p>.05 \)).

One-factor ANOVA was used to investigate the oncologist role in supporting cancer patients make high quality FP decisions. The total scores of the three standardized decision-making scales were used as dependent variables. Levene’s Test (\( p>.05 \)) was run to confirm homogeneity of variance before conducting the ANOVA tests.

The majority of participants wrote comments in one or more of the open-ended questions. Written comments were first grouped under each individual open-ended question. Thematic analysis (Boyatzis et al., 1998; Strauss & Corbin, 1998) using themes informed by FP psycho-social literature was conducted to gain a more detailed understanding of participant views in the decision-making process, as well as which aspects of the support they received or failed to receive from their oncologists contributed to their evaluation of it. These analyses complemented the quantitative responses in encapsulating the complexity and diversity of human experience and aiding the development of theoretical understanding (Charmaz, 2006). Extracts from the written
comments, where applicable, were cited in quotation to illustrate participant views in their own words.

4.4 Results

Table 9 lists the characteristics of the 49 women who saw a fertility specialist for FPC. Their mean age at diagnosis and current age were 30.2 (SD=3.8) and 33.3 (SD=4.2), respectively. Almost three quarters (n=36, 73.5%) were diagnosed within the three years before the time of survey completion. At the time of diagnosis, one-third were single (n=16, 32.7%) and three quarters were childless (n=37, 75.5%). Women who proceeded with fertility preservation after the FPC were compared with those who chose not to proceed (17 versus 32). Significantly more women in the FPP group were childless (94.1% versus 64.6%, p<.05) than women in the FPC group. Compared with the FPC participants, the women in the FPP group were more satisfied with how their oncologists handled the fertility discussion (76.5% versus 23.5%, p<.05), and more likely to report their oncologists were supportive of their FP plan (82.4% versus 34.4%, p<.05).

Table 9: Characteristics of 32 women who received a fertility preservation consultation and 17 women who proceeded with fertility preservation procedure (n=49, 32 versus 17)

<table>
<thead>
<tr>
<th>Socio-demographics at diagnosis</th>
<th>All n=49 (%)</th>
<th>FPC(^a) Group n=32 (%)</th>
<th>FPP(^a) Group n=17 (%)</th>
<th>p-value of (\chi^2)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age at diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td>.89</td>
</tr>
<tr>
<td>Between 18 and 29</td>
<td>22 (44.9%)</td>
<td>15 (46.9%)</td>
<td>7 (41.2%)</td>
<td></td>
</tr>
<tr>
<td>Between 30 and 34</td>
<td>18 (36.7%)</td>
<td>11 (34.4%)</td>
<td>7 (41.2%)</td>
<td></td>
</tr>
<tr>
<td>Between 35 and 39</td>
<td>9 (18.4%)</td>
<td>6 (18.8%)</td>
<td>3 (17.6%)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
<td>32 (100%)</td>
<td>17 (100%)</td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td>.21</td>
</tr>
<tr>
<td>White</td>
<td>44 (89.8%)</td>
<td>30 (93.8%)</td>
<td>14 (82.4%)</td>
<td></td>
</tr>
<tr>
<td>Non-white</td>
<td>5 (10.2%)</td>
<td>2 (6.3%)</td>
<td>3 (17.6%)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
<td>32 (100%)</td>
<td>17 (100%)</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td>.89</td>
</tr>
<tr>
<td>No university degree</td>
<td>15 (30.6%)</td>
<td>10 (31.3%)</td>
<td>5 (29.4%)</td>
<td></td>
</tr>
<tr>
<td>University degree</td>
<td>34 (69.4%)</td>
<td>22 (68.8%)</td>
<td>12 (70.6%)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
<td>32 (100%)</td>
<td>17 (100%)</td>
<td></td>
</tr>
<tr>
<td><strong>Individual income</strong></td>
<td></td>
<td></td>
<td>.34</td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td>--------</td>
<td>--------</td>
<td>--------</td>
<td></td>
</tr>
<tr>
<td>&lt; $30,000</td>
<td>9 (18.4%)</td>
<td>4 (12.5%)</td>
<td>5 (29.4%)</td>
<td></td>
</tr>
<tr>
<td>$30,000 to $50,000</td>
<td>16 (32.7%)</td>
<td>11 (34.4%)</td>
<td>5 (29.4%)</td>
<td></td>
</tr>
<tr>
<td>&gt; $50,000</td>
<td>24 (49%)</td>
<td>17 (53.1%)</td>
<td>7 (41.2%)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
<td>32 (100%)</td>
<td>17 (100%)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Had a child</strong></th>
<th>.03</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>12 (24.5%)</td>
</tr>
<tr>
<td>No</td>
<td>37 (75.5%)</td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Had a partner</strong></th>
<th>.72</th>
</tr>
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<tbody>
<tr>
<td>Yes</td>
<td>33 (67.3%)</td>
</tr>
<tr>
<td>No</td>
<td>16 (32.7%)</td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Cancer profiles</strong></th>
<th></th>
<th></th>
<th>.90</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Years since diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;=3 years</td>
<td>36 (73.5%)</td>
<td>23 (71.9%)</td>
<td>13 (76.5%)</td>
</tr>
<tr>
<td>4-6 years</td>
<td>9 (18.4%)</td>
<td>6 (18.8%)</td>
<td>3 (17.6%)</td>
</tr>
<tr>
<td>&gt;7 years</td>
<td>4 (8.2%)</td>
<td>3 (9.4%)</td>
<td>1 (5.9%)</td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
<td>32 (100%)</td>
<td>17 (100%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Cancer type</strong></th>
<th>.85</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>25 (51%)</td>
</tr>
<tr>
<td>Others</td>
<td>24 (49%)</td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Cancer stage</strong></th>
<th>.45</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1 or 2</td>
<td>29 (59.2%)</td>
</tr>
<tr>
<td>Stage 3 or 4</td>
<td>18 (36.7%)</td>
</tr>
<tr>
<td>Not specified</td>
<td>2 (4.1%)</td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Degree of fertility concern at diagnosis</strong></th>
<th>.15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low (1 &amp; 2)</td>
<td>5 (10.2%)</td>
</tr>
<tr>
<td>Medium (3)</td>
<td>5 (10.2%)</td>
</tr>
<tr>
<td>High (4 &amp; 5)</td>
<td>39 (79.6%)</td>
</tr>
<tr>
<td>Perceived quality of fertility discussion with oncologists</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------</td>
<td>---</td>
</tr>
<tr>
<td><strong>Initiation of discussion</strong></td>
<td></td>
</tr>
<tr>
<td>Patient-initiated</td>
<td>26 (53.1%)</td>
</tr>
<tr>
<td>Oncologist-initiated</td>
<td>23 (46.9%)</td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
</tr>
<tr>
<td><strong>Satisfaction of discussion</strong></td>
<td></td>
</tr>
<tr>
<td>Dissatisfied or neutral</td>
<td>24 (49%)</td>
</tr>
<tr>
<td>Satisfied</td>
<td>25 (51%)</td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
</tr>
<tr>
<td><strong>Perceived support from oncologists of the FP plan</strong></td>
<td></td>
</tr>
<tr>
<td>Non-supportive or neutral</td>
<td>24 (49%)</td>
</tr>
<tr>
<td>Supportive</td>
<td>25 (51%)</td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
</tr>
<tr>
<td><strong>Most preferred medical decision making style using the Control Preferences Scale</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Active</strong></td>
<td></td>
</tr>
<tr>
<td>I prefer to make the decision about which treatment I will receive</td>
<td>7 (14.3%)</td>
</tr>
<tr>
<td>I prefer to make the final decision about my treatment after seriously considering my doctor’s opinion</td>
<td>15 (30.6%)</td>
</tr>
<tr>
<td><strong>Collaborative</strong></td>
<td></td>
</tr>
<tr>
<td>I prefer that my doctor and I share responsibility for deciding which treatment is best for me</td>
<td>13 (26.5%)</td>
</tr>
<tr>
<td><strong>Passive</strong></td>
<td></td>
</tr>
<tr>
<td>I prefer that my doctor make the final decision about which treatment will be used about seriously consider my opinion</td>
<td>11 (22.4%)</td>
</tr>
<tr>
<td>I prefer to leave all decisions regarding treatment to my doctor</td>
<td>3 (6.1%)</td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
</tr>
</tbody>
</table>

*Fertility preservation consultation: FPC; fertility preservation procedure (FPP)*
4.4.1 Medical decision-making styles

Table 9 also shows the participant order of preference for medical decision making styles ranked by the Control Preferences Scale. The most preferred decision-making style was participants wanting to make their own treatment decision after seriously considering their doctors’ opinions (n=15, 30.6%), followed by making a joint decision with their doctors (n=13, 26.5%). Regardless of the decision-making styles, participants wanted their oncologists to be empathetic to their wishes to have children and listen to their concerns about fertility: “Preserving my fertility didn’t matter at all to my doctors but it meant everything to me…. losing my fertility had the biggest emotional impact on my life.” (Diagnosed at age 30, married with one child). They also wanted their doctors to be respectful of their desire for motherhood and not to impose their personal opinions onto them:

“In my view, my oncologist’s role is to provide me with the medical information I am seeking, not his/her personal opinion. The decision to have or not to have more children should be mine to make based on solid information provided” (Diagnosed at age 34, separated with one child)

4.4.2 Fertility preservation decision

The majority of FPC referrals were made by medical oncologists (n=22, 44.9%) and surgical oncologists (n=10, 20.4%), followed by gynecologic oncologists (n=6, 12.2%). The average waiting time to see a fertility specialist was within a few days (n=23, 46.9%), between 1 and 2 weeks (n=15, 30.6%), and between 2 and 3 weeks (n=6, 12.2%). Unfortunately, 5 women (10.2%) had to wait for more than 3 weeks for a FPC appointment.

Of the 49 participants who consulted a fertility specialist, 17 (34.7%) chose to undergo in-vitro fertilization to preserve unfertilized oocytes and/or embryos: 4 women cryopreserved their unfertilized oocytes, 9 cryopreserved their embryos using partner sperm, 3 cryopreserved their embryos using donor sperm, and 1 cryopreserved both unfertilized oocytes as well as embryos using donor sperm. Table 10 shows the participant choices of FP methods by their relationship
status at the time of cancer diagnosis. No participants used experimental fertility preservation procedures such as ovarian tissue banking. At the time of survey, 6 of the 17 women indicated that they had returned to the clinic to use their cryopreserved oocytes and embryos, of whom one woman had a successful live birth, four were in the preparation stage to start an embryo transfer cycle, and one woman had a failed outcome from her embryo transfer cycle.

Table 10: Participants’ choice of fertility preservation methods by their relationship status at the time of diagnosis (n=17)

<table>
<thead>
<tr>
<th></th>
<th>Single n=5 (%)</th>
<th>Married or partnered n=12 (%)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chose to freeze eggs</td>
<td>2 (40%)</td>
<td>2 (16.7%)</td>
<td>4 (23.5%)</td>
</tr>
<tr>
<td>Chose to freeze embryos with partner’s sperm</td>
<td>0</td>
<td>9 (75%)</td>
<td>9 (52.9%)</td>
</tr>
<tr>
<td>Chose to freeze embryos with donor sperm</td>
<td>2 (40%)</td>
<td>1 (8.3%)</td>
<td>3 (17.6%)</td>
</tr>
<tr>
<td>Chose to freeze eggs and embryos with donor sperm</td>
<td>1 (20%)</td>
<td>0</td>
<td>1 (5.9%)</td>
</tr>
<tr>
<td>Total</td>
<td>5 (100%)</td>
<td>12 (100%)</td>
<td>17 (100%)</td>
</tr>
</tbody>
</table>

Most women (77.6%) reported having ‘a lot’ of time pressure in the FP decision-making process. The majority also reported experiencing ‘a lot’ of uncertainty (57.1%) and psychological stress (51%) at the time of decision-making. Thirty-two women decided not to proceed with FP after their FPC. The time pressure experienced by participants was well captured in one comment: “It was all thrown on us so quickly I feel I wasn't given a chance to make an adequate decision. I chose not to proceed but mostly because I felt pressure to hurry up and start chemo/radiation.” (Diagnosed at age 32, married, no children). Another woman shared her struggles of how her relationship status and financial strain at diagnosis influenced her decision of not proceeding with FP:

“The clinic was supportive, even offered me a subsidized deal - I would have to get a loan for the process, find sperm, have estrogen
stimulation etc. It was ALL too overwhelming. I didn’t have the money, could not get the loan, had just started dating and could not ask for sperm and coordinate all of that, it was ALL logistically seemingly IMPOSSIBLE!” (Capitals in original) (Diagnosed at age 37, single, no children)

Logistic regression analyses were used to assess the factors associated with the odds of the uptake of FP procedure. Univariate logistic regression analyses were conducted first using 6 socio-demographic variables, 3 cancer profile variables, 1 fertility concern variable, and three fertility discussion variables from Table 11 to evaluate the magnitude of effects on the uptake of FP. Five variables with a $p<.20$ in the univariate logistic regression analyses associated with FP uptake were used for logistic regression analysis using two blocks. Patient factor variables (i.e. motherhood status and fertility concern) for block 1, and fertility discussion variables (i.e. initiation of fertility discussion, levels of satisfaction of fertility discussion with oncologists, and perceived support from oncologists of their FP plan) for block 2. Table 11 shows the results of the logistic regression analyses. Participant levels of fertility concerns at diagnosis ($p<.05$) and the perception that their FP plan was supported by their oncologists ($p<.05$) were found to be significant in predicting the decision to proceed with FP subsequently after the FPC.

After taking account of other variables in the model, the odds of the uptake of FP for women who found their oncologists supportive of their FP plan were seven times higher compared with others who found their oncologists either non-supportive or neutral. The odds increased by five times for each additional unit on the 5-point Likert scale examining the fertility concern of participants at the time of cancer diagnosis.
Table 11: Logistic regression analysis of the uptake of fertility preservation procedure (n=49, 32 versus 17)

<table>
<thead>
<tr>
<th></th>
<th>All n=49 (%)</th>
<th>Model 1 OR (95% CI)</th>
<th>Model 2 OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BLOCK 1: Patient factors</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had a child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>12 (24.5%)</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>No</td>
<td>37 (75.5%)</td>
<td>9.34 (1.04 to 84.07)</td>
<td>4.15 (.33 to 51.78)</td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fertility concern at diagnosis (5-point Likert Scale)</td>
<td>49 (100%)</td>
<td>2.95 (1.08 to 8.06)</td>
<td>5.61 (1.44 to 21.92)</td>
</tr>
<tr>
<td><strong>BLOCK 2: Fertility discussion with oncologists</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who initiated the fertility discussion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient-initiated</td>
<td>26 (53.1%)</td>
<td>--</td>
<td>1.0</td>
</tr>
<tr>
<td>Oncologist-initiated</td>
<td>23 (46.9%)</td>
<td>1.55 (.20 to 11.98)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Levels of satisfaction of fertility discussion with oncologists</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dissatisfied or neutral</td>
<td>24 (49%)</td>
<td>--</td>
<td>1.0</td>
</tr>
<tr>
<td>Satisfied</td>
<td>25 (51%)</td>
<td>3.22 (.54 to 19.12)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived support from oncologists of the FP plan</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-supportive or neutral</td>
<td>24 (49%)</td>
<td>--</td>
<td>1.0</td>
</tr>
<tr>
<td>Supportive</td>
<td>25 (51%)</td>
<td>7.21 (1.01 to 51.56)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>49 (100%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a OR: odds ratio. CI: Confidence interval
b p<.05
c Nagelkerke R² for Block 1=.322, p<.005
d Change in Nagelkerke R² associated with Block 2=.243, p<.01
Full model Nagelkerke R²=.565, p<.001

4.4.3 Oncologist influence on the uptake of fertility preservation

Table 9 also shows the participant perceived quality of fertility discussions with their oncologists between the FPC and FPP groups. The decision to proceed with FP was found to be significantly associated with whether the women were satisfied with the pre-FPC fertility discussions they had with their oncologists (p<.01), and whether they found their oncologists
supportive of their FP plan \( (p<.01) \). There was a statistical trend \( (p=.07) \) indicating that women who proceeded with FPP were more likely to have had their original FP discussion initiated by their oncologists.

Of the 25 participants (51%) who found their oncologists supportive of their FP plan, two-thirds (68%) reported their oncologists were was the one who initiated the fertility discussion, and 4 out of 5 (80%) were satisfied with the way the fertility discussion was handled. In contrast, only 1 in 5 (20.8%) women who found their oncologists ‘non-supportive’ or ‘neutral’ were themselves satisfied with the fertility discussion (analyses not shown).

In addition, the participant perceived support from their oncologists of their FP plan was highly associated with the perceived quality of the initial fertility discussion they had with their oncologists before they were referred to see a fertility specialist. This include whether the fertility discussions were patient- or oncologist-initiated \( (p<.01) \) and whether they were satisfied or not with the discussion \( (p<.01) \). Significant association was also found between the initiation of discussion and the levels of satisfaction \( (p<.05) \).

### 4.4.4 Quality of fertility preservation decision

Participant appraisal of the quality of their FP decision was evaluated by the total scores of three decision-making variables: the Informed Choice Scale, the Satisfaction with Decision Scale, and the Decision Regret Scale. Regardless of the FP decision, the mean score of the Decision Regret Scale was low \( (\text{mean}=10.98, \ SD=5.78, \ range \ 5-25) \). The mean score of the Informed Choice Scale was moderate \( (\text{mean}=15.92, \ SD=5.38, \ range \ 5-25) \) and the mean score of the Satisfaction with Decision Scale was moderately high \( (\text{mean}=18.1, \ SD=6.36, \ range \ 5-25) \). Furthermore, the Decision Regret scores were found to be negatively correlated with both the Informed Choice scores \( [r_{(49)}=-.70, \ p<.01] \) and the Satisfaction with Decision scores \( [r_{(49)}=-.85, \ p<.01] \). On the other hand, the Informed Choice and the Satisfaction With Decision scores were positively correlated \( [r_{(49)}=.83, \ p<.001] \).
4.4.5 Oncologist influence on the quality of FP decision

The three decision-making scales were further analyzed by one-factor ANOVA using three
categorical variables related to participant perceived quality of fertility discussions with their
oncologists prior to their fertility preservation consultation. These include 1) whether the initial
fertility discussion was patient- or oncologist- initiated, 2) whether they were ‘satisfied’ or
‘dissatisfied or neutral’ with the fertility discussion, and 3) whether their oncologists were
‘supportive’ or ‘non-supportive or neutral’ of their FP plan.

Compared with the patient-initiated discussion group, the oncologist-initiated group had
significantly lower Decision Regret scores *(mean=9.13 versus mean=12.62), [F(1,47)=4.76, p<.05,
\( \eta^2=.09 \)]*, and significantly higher Satisfaction with Decision scores *(mean=20.91 versus
mean=15.62), [F(1,47)=10.06, p<.005, \( \eta^2=.18 \)]* and Informed Choice scores *(mean=18.13 versus
mean=13.96), [F(1,47)=8.47, p<.01, \( \eta^2=.15 \)]*.

Compared with the women who were ‘dissatisfied’ or ‘neutral’ with the discussion, the
‘satisfied’ group had significantly lower Decision Regret scores *(mean=8.84 versus mean=13.21),
[F(1,47)=7.97, p<.01, \( \eta^2=.15 \)]* and significantly higher Informed Choice scores *(mean=18.96 versus
mean=12.75), [F(1,47)=24.19, p<.001, \( \eta^2=.34 \)]*.

Compared with the women who found their oncologists ‘non-supportive or neutral’ of their
FP plan, the ‘supportive’ group had significantly lower Decision Regret scores *(mean=8.68 versus
mean=13.38), [F(1,47)=9.46, p<.01, \( \eta^2=.17 \)]* and significantly higher Informed Choice scores *(mean=18.40 versus mean=13.33), [F(1,47)=13.74, p<.005, \( \eta^2=.25 \)]*.

4.4.6 Decision appraisal in retrospect

Between the time of cancer diagnosis and survey time, one woman had separated from
her partner and five single women had begun a partnered/married relationship. Reflecting upon
the FP decision made at the time of cancer diagnosis, most participants wrote descriptive
comments to further elaborate on the challenges they had encountered during the decision-
making process. One breast cancer survivor decided not to preserve fertility despite her strong desire for motherhood:

“\(\text{I was still trying to deal with accepting the diagnosis, the loss of my breasts, healing, pain and fatigue, as well as trying to absorb all of the information from the specialist and make critical decisions. I felt a great deal of pressure because I would have to start the hormone injections immediately in order to have enough time to harvest before I was scheduled to begin chemo. The specialist did not pressure me and was very helpful, but the situation itself created the pressure. I also wanted to be able to discuss the situation with my oncologist prior to taking hormone injections, but there was not enough time. Ultimately, I opted to take a chance and not fertilize and freeze eggs because I could not fathom injecting my body with hormones for two weeks then going through egg harvesting one week before chemo and only three weeks after a double mastectomy. The whole experience was extremely stressful and emotional.}’’ \(\text{(Diagnosed at age 34, separated, one child)}\)

When evaluating the quality of the FP decision in retrospect, a few participants commented on their ambivalence at the time of FP decision-making while dealing with a life threatening illness. One woman who could not preserve fertility before her cancer treatment recalled her devastation of not being able to undergo the procedure due to the urgency of starting chemotherapy: “It was a heart-breaking decision, but there was no other choice for me. Delaying chemo would have been life-threatening” \(\text{(Diagnosed at age 37, married, no children). Some women made a deliberate choice of not preserving fertility in favor of initiating cancer treatment sooner to optimize their survival chances:}\\)

“The priority at the time was to get rid of treatment......Preserving eggs would have taken some time....I have wondered since then,\(\)
’what if?’ But I would have died within 2 years of that diagnosis. If being alive 10 years later (and beyond) means I can't have kids, so be it. It'll be tough, but it's not a bad deal.” (Diagnosed at age 19, single, no children)

One participant who was single at the time of decision-making made a decision to leave her fertility to fate due to her personal circumstance:

“I grappled with being at the most unhealthy I had ever been and the thought of preserving eggs at the time when I was mentally and physically at an all time low did not seem to be the most appealing. I preferred to leave it to fate later on. It is such a personal decision, and for me, the timing wasn't right. The thought of telling a potential boyfriend that I had frozen eggs or frozen embryo just wasn't a discussion I wanted to have.” (Diagnosed at age 27, single, no children)

At the time of survey completion, a few participants remained uncertain if they had made a good decision of not proceeding when they were given a chance to preserve fertility:

“To this day I am not sure if I made the right decision at the time...I was stressed and in a time crunch, so I made the best decision I could at the time.... It is extremely difficult to digest a cancer diagnosis and all of the potential ramifications, once you decide you want to live and to make that happen then you have to weigh all of the risks associated with future plans, including having children.” (Diagnosed at age 34, separated, one child)

One partnered woman shared her regrets of not pursuing FP and how this decision affected her marriage:
“We chose not to do fertility......This is the only decision I have ever regretted in my lifetime. It has almost ruined my marriage as my husband doesn't want anything other than child from him and me. I wish every day they had told us to discuss it and make another appointment to give our final response.” (Diagnosed at age 31, married, no children)

4.5 Discussions

4.5.1 Factors associated with the uptake of fertility preservation

Our data were collected after a FP decision was made and active cancer treatments had completed. The average age of participants at the time of cancer diagnosis was 30, and the average time gap between the diagnosis and survey time was only three years. Since the majority of participants were still in their prime years of childbearing, it is reasonable to expect that some of them might have already experienced late side effects of cancer treatment on their fertility.

Of the 49 women who received FPC in our study, only one-third took action to preserve their fertility after consulting a fertility specialist. This percentage is substantially lower than figures reported by studies where their participants were recruited directly from FP programs affiliated with academic institutions (Bastings et al., 2014b; Hill et al., 2012; Kim et al., 2013; Klock et al., 2010; S. Lee et al., 2011). However, similarly low uptake rates of FP following a FPC were also reported in other studies using local cancer registries. Of the 45 women who received FP information in Armuand et al. (2012), only 15.6% proceeded with FP. In another study conducted by Goodman et al. (2012), only 27% of the 41 women underwent a FP procedure following a FP discussion. The variation in the FP uptake rates could be due to recruitment factors, sample sizes, participant characteristics, and cancer profiles.

Previous studies suggest that certain patient factors and socio-demographic characteristics are influential in FP decision-making. These include childlessness at diagnosis (Kim et al., 2013), relationship status (Hill et al., 2012; Letourneau et al., 2012a), having a strong desire for future children (Kim et al., 2013), and having a high fertility concern (Letourneau et al., 2012a). In this...
study, we found no significant differences between women who chose to preserve fertility or not to take action following the consultation in regard to their age, ethnicity, relationship status, education, income, and cancer history. On the other hand, almost all participants who proceeded with FP were childless; a finding contradicted by a Canadian survey study where they found motherhood status was not significantly associated with participant FP decision (Hill et al., 2012). Furthermore, we found that participants who chose to proceed with FP were more likely to be satisfied with how their oncologists handled the fertility discussions and were likely to find their oncologists supportive of their FP plan.

For many cancer patients, the narrow window of time in decision-making usually coincides with the emotional turmoil of receiving a cancer diagnosis, dealing with the uncertainty of cancer prognosis, and making plans for cancer treatment (Degner et al., 1997; Peate et al., 2012). In this study, the two factors that were found to be significantly associated with the uptake of FP were participant levels of fertility concern at diagnosis and participant perception of support from their oncologists of their FP plan. Since over 90% of our participants had cancer treatments that were potentially gonadotoxic to reproductive functions and all of them had a fertility discussion with their oncologists concerning their fertility risks before the FPC, it is quite understandable that most of them had high levels of fertility concerns. It is also quite likely that they would seek medical opinions from their oncologists post FPC when their FP decision had implications on their cancer treatment plan.

Studies show that the majority of cancer patients were influenced by the recommendations of their medical oncology team when making a FP decision (Mersereau & Sandbulte, 2013; Peddie et al., 2012). A study surveying cancer patients FPC experiences found that 79% consulted their oncologist for decision-making after receiving the FPC and a quarter reported receiving conflictual medical advice from different health care providers about FP options and cancer treatments (Kim et al., 2013). Good doctor-patient communication can enhance informed decision-making and treatment satisfaction (Blank, Graves, Sepucha, & Llewellyn-Thomas, 2006). On the contrary, poor communication on fertility matters can negatively impact patient FP decision-making capacity by creating stress, uncertainty, confusion, and decisional conflicts; thus, hindering their confidence in
making satisfactory and informed medical decisions (Duffy et al., 2005; Niemasik et al., 2012; Penrose et al., 2012; Wilkes et al., 2010).

4.5.2 Decision-making style and quality of the fertility preservation decision

The most preferred decision-making style of participants in this study was to make their own decision after considering doctors’ opinion. Less than one-fifth chose the extreme style of either making medical decisions on their own (14.3%) or leaving the decisions to their doctors (6.1%). Decision-making is an interactive process involving both parties to share information and make negotiations to reach an agreement (Kriston, Scholl, Hölzel, Simon, Loh, & Härter, 2010). Studies of other treatment decision-making show that patients who were actively involved in their own treatment had more confidence in their treatment decision and were more hopeful in their treatment outcomes compared with those who were less involved (Degner et al., 1997; Hack, Degner, & Dyck, 1994; Petersen, Heesacher, & Marsh, 2001). Making a high quality decision involves exercising autonomy and making good judgments in order to balance personal gains against losses (Peate et al., 2012; Petersen et al., 2001). The preferred style of self-agency in decision-making after considering doctors’ advice reported by our participants is not a surprise, since 70% were university educated and over 80% of them were young women under age 35 with a mean age of 30 when a diagnosis was received. Well-educated and younger patients are more inclined to seek information, learn the details of their illness and treatment, advocate for their needs, and participate in decisions about their care (Cameron, 2009; Peate et al., 2012).

Previous work suggests that decisional regret, informed choice, and decision satisfaction are related, but represent distinct aspects of decision quality (Brehaut et al., 2003). Good quality decisions are found to be negatively associated with decisional conflict and post-decision regret, and positively associated with good health outcomes, positive emotions, and life satisfaction (Kim et al., 2013; Mersereau & Sandbulte, 2013). In this study, we found that participants had low post-decision regret when they reported that their FP choice was well informed. Even for those who chose not to proceed with FP, the total scores of the three decision-making scales reached an acceptable level. Similar observations were found in studies where cancer survivors who received FPC had lower levels of decision regret and decisional conflicts in comparison to those who did not
receive FPC and were unaware of their FP options prior to commencing cancer treatments (Bastings et al., 2014b; Letourneau et al., 2012a; Mersereau & Sandbulte, 2013).

The majority of women in our study reported having an enormous amount of stress and time pressure during the decision-making process. Heightened stress and constrained time in decision-making can interfere with a person’s ability to think clearly, process information efficiently, and make rational judgments that are geared to her personal values (Geue et al., 2014; Kim et al., 2013). Studies surveying breast cancer patients found that 32% reported having high levels of anxiety during the FP decision-making (Peate et al., 2011); 39% expressed having difficulties in making a FP decision due to the time pressure (Hill et al., 2012). Another US study found that women who declined FP were more likely to be in a state of shock upon learning their cancer diagnosis and did not have the emotional strength to undergo a FP procedure (Klock et al., 2010). Although FP procedures can be accomplished with minimal delay in cancer treatment (Noyes et al., 2013), FP referrals immediately after a diagnosis give patients more FP options using established procedures (S. Lee et al., 2011) and better FP outcomes (Lee et al., 2010). Not only would early FP referrals afford patients time to have a follow-up meeting with the fertility specialist (Balthazar et al., 2012a), it would give patients additional time to seek input from their oncologists before making a critical FP decision that has long-term implications on their future childbearing plan (Kim et al., 2013).

Fertility preservation is a time-sensitive medical procedure, the time pressure in decision-making is even more so for cancer patients to avoid causing a life threatening delay of initiating cancer treatment. The decision of whether to preserve fertility or not usually needs to be made shortly after a single FPC visit. A study by Kim and colleagues (2013) found that the amount of time needed for completing FP treatment was a key factor influencing the FP decision for cancer patients. In this study, nearly half of the participants reported the average waiting time to see a fertility specialist was within a few days. This short waiting time is encouraging as it shows that most Canadian fertility clinics gave priority to cancer referrals to accommodate the urgent medical needs of these cancer patients (Yee et al., 2012b).
4.5.3 Role of oncologists in supporting patient made fertility preservation decisions

Numerous studies exploring oncologist-patient communication on fertility matters found that a significant portion of female survivors recalled being dissatisfied with the quality of fertility discussion or the quantity of received information (Adams et al., 2013; Duffy et al., 2005; Partridge et al., 2004; Peate et al., 2009; Peate et al., 2012). Some felt their fertility concerns were not well managed and fertility risks associated with cancer treatment were inadequately explained (Penrose et al., 2012; Kirkman et al., 2013; Yeomanson et al., 2013). A study by Basting et al. (2014b) found that patients who did not feel supported by their oncologist had high decisional conflicts and post-decision regrets in their FP decision.

Among the participants who proceeded with FP, nearly two-thirds of their pre-FPC fertility discussions were initiated by oncologists and three quarters were satisfied with how their oncologists handled the fertility discussion. Conversely, participants who reported having a negative oncologist-patient communication experience regarding fertility matters were much more inclined not to pursue FP in the end. Our study found that not only was the proactivity of oncologists in initiating a fertility discussion important, the qualities of the discussion were equally critical in supporting patients in FP decision-making. Our findings show that oncologists play a pivotal role in FP services in that they are not only gate keepers, knowledge brokers, and referral initiators of FPC, they are catalysts in supporting cancer patients making high quality FP decision in conjunction with the FPC provided by a fertility specialist.

4.6 Limitations

The study has several limitations. The sample size is small, which limits the study’s power to detect significant effects. However, the majority of published FP survey studies had small sample sizes, ranging from 27 to 65 (Balthazar et al., 2011; Balthazar et al., 2012; Bastings et al., 2014b; Hill et al., 2012; Kim et al., 2013; Klock et al., 2010). The cross-sectional survey design limits one’s ability to determine causality. Participants completed the survey voluntarily in response to recruitment flyers and were self-selected to participate in this study. There is a potential selection bias as they may have more personal interests in fertility preservation issues, leading to greater extremes in more positive or negative feelings regarding their FP decision. Nonetheless, our
findings provide novel information of the pivotal role by Canadian oncologists in supporting patients when a FP decision needs to be made urgently to avoid any delay in commencing cancer treatment. Prospective studies are needed to confirm the causal nature of the association between the quality of fertility discussion with oncologists and patient confidence in making an informed and satisfactory FP decision.
5.1 Synthesis of major findings

The overarching goal of this study is to identify the factors associated with young Canadian female cancer patients having a fertility discussion with their oncologists, and with receiving fertility preservation services provided by a fertility specialist prior to commencing cancer treatment. The research was guided by the new Integrated Fertility Preservation Decision-Making Framework (please refer to Figure 1 on p.14) developed in my comprehensive paper (Yee, 2011). This synthesized model draws upon the Transaction Model of Stress and Coping Theory (Lazarus & Folkman, 1994), Theory of Uncertainty in Illness Model (Mishel, 1990, 1998), Hope Theory (Snyder, 2002; Snyder et al., 2000), and Health Belief Model (Rosenstock, 1974, 1990). This framework conceptualizes the fertility preservation decision-making pathway used by young women newly diagnosed with cancer.

Specifically, this study investigates three research questions exploring the receipt of fertility-related aspects at three different decision-making points depicted in this framework (Figure 1). First, what are the factors associated with young cancer patients having a fertility discussion with their oncologists at the time of receiving a cancer diagnosis? (n=188, 45 versus 143). Second, what are the factors associated with consulting a fertility specialist to discuss their pre-cancer treatment fertility preservation options following a fertility discussion? (n=143, 94 versus 49). Third, what are the factors associated with their decision to preserve fertility following a fertility preservation consultation? (n=49, 32 versus 17).

Among the 188 young female cancer survivors who participated in this online survey, nearly one quarter (n=45, 23.9%) did not recall having a fertility discussion with any oncologist at the time of cancer diagnosis. It is of concern to learn that one quarter of cancer patients had no fertility discussion at all with any oncologist during the time of their cancer diagnosis. This finding suggests that a significant portion of Canadian oncologists were inattentive to the fertility needs of their cancer patients. This finding is consistent with the figures reported in two other large scale web-
based surveys where 20% (Tschudin et al., 2010) and 28% (Partridge et al., 2004) of female cancer survivors had no fertility discussion with their doctors at the time of cancer diagnosis.

Surveys on oncologist attitudes and practice behaviors related to fertility preservation also found that oncologists were inconsistent and selective in discussing fertility concerns with their cancer patients (Duffy et al., 2012; Quinn et al., 2009). Two recent studies examining oncologist attitudes on fertility matters found that nearly one-third of the respondents rarely took a woman’s fertility desire into consideration when planning cancer treatments (Forman et al., 2010; Ghorbani et al. 011). Other oncologist surveys found that one quarter did not think it was their clinical responsibility to bring up fertility issues during cancer care (Duffy et al., 2012) and 40% insisted that cancer patients should bring up the fertility topic themselves if they wanted to get information (Ghorbani et al., 2011).

Of the three quarters of our survey participants who had a fertility discussion (n=143, 76.1%) with their oncologists, discussions were equally initiated by oncologists (n=71) and patients (n=72). As half of the fertility discussions were initiated by cancer patients, it is quite likely that many of these fertility discussions would not have occurred if patients did not take the initiative to inquire about fertility information (Shimizu et al., 2013; Quinn & Vadaparampil, 2009). It is worrisome that 38.3% of the full sample had to initiate the fertility discussion with their oncologists. A study conducted by Garvelink and colleagues (2013) in the Netherlands reported that one-third of their participants initiated a fertility discussion with their oncology health providers in order to get information. Prior studies also noted that women who wanted to have children after completing their cancer treatment were more likely to inquire about future pregnancy implications at the time of making plans for cancer treatment (Gorman et al., 2012; S. Lee et al., 2011; Penrose et al., 2012).

Of the 51 women (27% of the full sample) who were referred by their oncologists to a fertility specialist for a pre-cancer treatment fertility preservation consultation, 49 (26%) consulted a fertility specialist to receive personalized medical information about their cryopreservation options. Numerous studies investigating the receipt of fertility preservation consultations in
female cancer patients have found low utilization of services, with only 5% to 24% of women consulting a fertility specialist for pre-cancer treatment cryopreservation options (Bastings et al., 2014b; Geue et al., 2014; Goodman et al., 2012; Letourneau et al., 2012b; Niemasik et al., 2012; Partridge et al., 2004). The fertility preservation consultation rate of one in four in the current study is consistent with the percentages reported in these reports.

Of the 92 women who had a fertility discussion with their oncologists but were not referred to a fertility specialist to discuss fertility preservation options, 44% indicated that they would like to have seen a fertility specialist if they were given a chance. It is disturbing to find that many of our survey participants were not given a choice to consult a fertility expert despite their interests in receiving the services. Surveys on cancer survivors found that speaking to a fertility specialist on the efficacy, benefits, risks, success rates, and costs associated with cryopreservation procedures was their preferred way of obtaining personalized fertility preservation information in order to make an informed medical decision (Peate et al., 2009; Thewes et al., 2005). This finding confirms other reports that many cancer patients value the opportunity to learn about their fertility preservation options in order to make a properly informed choice (Gorman et al., 2011; Gorman et al., 2012; S. Lee et al., 2011; Penrose et al., 2012).

Among the 49 participants who consulted a fertility specialist, 32 (65.3%) women chose not to proceed with fertility preservation following the consultation; only 17 (34.7%) underwent a fertility preservation procedure to preserve unfertilized oocytes and/or embryos. This represents less than 10% of the full sample of 188 women. Of those who chose to preserve fertility, 4 women cryopreserved their unfertilized oocytes, 9 cryopreserved their embryos using partner sperm, 3 cryopreserved their embryos using donor sperm, and 1 cryopreserved unfertilized oocytes as well as embryos using donor sperm. Our finding of the cryopreservation procedure uptake rate is substantially lower than figures reported in other studies, possibly because these studies recruited participants directly from fertility preservation programs affiliated with academic institutions (Bastings et al., 2014b; Hill et al., 2012; Kim et al., 2013; Klock, et al., 2010; S. Lee et al., 2011). In contrast to these studies, low fertility preservation uptake rates, as with the findings in the current study, were reported in other surveys where the participants were recruited through local cancer
registries but not from fertility preservation programs (Armuand et al., 2012; Goodman et al., 2012).

In the first inquiry (n=188), the only significant factor associated with cancer patients having a fertility discussion with their oncologists, irrespective of whether the discussion was initiated by the patient or oncologist, was high patient fertility concern at the time of cancer diagnosis \( (p<.001) \) (Table 12). When interpreting this finding, it is important to recognize that the fertility needs of young women could be overshadowed by their cancer diagnosis and treatments when survival takes priority, and their reproductive concerns may arise after the acute phase of cancer treatment is passed (Gorman et al., 2012; Penrose et al., 2012). Therefore it is quite plausible that the participants who did not have a high fertility concern at cancer diagnosis may have lacked knowledge of fertility risks associated with their cancer treatment, and their lack of fertility concern at diagnosis may not be due to a lack of desire to procreate. Our findings have concurred with other reports suggesting that women who are passive or emotionally preoccupied with their cancer diagnosis may not receive essential information if they do not bring up the fertility topic themselves (Garvelink et al., 2013; Vadaparampil et al., 2012).

When assessing factors associated with fertility discussions initiated by oncologists without patient prompting, fertility concern was not significant in either the bivariate or logistic regression analyses (Table 13). In the bivariate analyses, significantly more women in the oncologist-initiated discussion group had a partner \( (70.4\% \text{ versus } 55.6\%, \ p<.05) \), earned an annual income above $30,000 \( (81.7\% \text{ versus } 65\%, \ p<.05) \), were diagnosed with cancer within 6 years prior to survey completion \( (53.8\% \text{ versus } 62\%, \ p<.05; \ 23.9\% \text{ versus } 32.4\%, \ p<.05) \), and had cancer treatments that were gonadotoxic \( (87.3\% \text{ versus } 74.4\%, \ p<.05) \), compared to women whose oncologists did not initiate a fertility discussion with them. Prior studies conducted in the UK and US found that patients’ parental status influenced the decision of 10% to 45% of surveyed oncologists in initiating fertility discussions (Adams et al., 2013; Forman et al., 2010). Women who were childless at diagnosis (Duffy et al., 2005; Vadaparampil et al., 2012) were more likely to receive fertility information provided by an oncology team. In contrast to these reports, participants’ motherhood status was not found to be a significant determinant in having an oncologist-initiated discussion.
However, we found that partnered women and those who earned an annual income above $30,000 were over represented in the oncologist-initiated discussion group. Our findings suggest that oncologists may deliberately refrain from initiating fertility discussions based on patients’ relationship status and income. These assumptions could hinder equity of access to fertility information.

On the other hand, when multiple factors were included in the logistic regression model to investigate the odds of having an oncologist-initiated fertility discussion, the only significant predictor was the reception of a cancer diagnosis after the year 2006 – the year that the American Society of Clinical Oncology (ASCO) published their clinical practice guidelines on fertility preservation (Lee et al., 2006). We found that 42% of women diagnosed with cancer after 2006 had an oncologist-initiated fertility discussion compared to only 13% of women who had cancer between 2000 and 2006. Thus, women who received a cancer diagnosis after 2006 had more than

Table 12: Factors associated with having a fertility discussion with oncologists (n=188, 45 versus 143).

<table>
<thead>
<tr>
<th>Block 1: Socio-demographics at diagnosis</th>
<th>Bivariate analysis χ²</th>
<th>Multivariate logistic regression model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Place of residence</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Had a university degree</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Individual income &gt; $30,000</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Had no children</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Had a partner</td>
<td>NS</td>
<td>NS</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Block 2: Cancer profiles</th>
<th>Bivariate analysis χ²</th>
<th>Multivariate logistic regression model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years since diagnosis</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Received gonadotoxic cancer treatment</td>
<td>NS</td>
<td>NS</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Block 3: Fertility concern at diagnosis</th>
<th>Bivariate analysis χ²</th>
<th>Multivariate logistic regression model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had a high level of fertility concern</td>
<td>p&lt;.001</td>
<td>OR 5.22 (95% CI: 2.14 to 12.72), p&lt;.001</td>
</tr>
</tbody>
</table>
Table 13: Factors associated with having an oncologist-initiated fertility discussion (n=188, 117 versus 71).

<table>
<thead>
<tr>
<th>Block 1: Socio-demographics at diagnosis</th>
<th>Bivariate analysis $\chi^2$</th>
<th>Multivariate logistic regression model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Place of residence</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Had a university degree</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Individual income &gt; $30,000</td>
<td>p&lt;.05</td>
<td>NS</td>
</tr>
<tr>
<td>Had no children</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Had a partner</td>
<td>p&lt;.05</td>
<td>NS</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Block 2: Cancer profiles</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Years since diagnosis (&lt;=3 years &amp; 4-6 years)</td>
<td>p&lt;.05</td>
<td>OR 3.68 (95% CI: 1.10 to 12.26), p&lt;.05 OR 4.87 (95% CI: 1.35 to 17.54), p&lt;.05</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Received gonadotoxic cancer treatment</td>
<td>p&lt;.05</td>
<td>NS</td>
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<table>
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<tr>
<th>Block 3: Fertility concern at diagnosis</th>
<th></th>
<th></th>
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<tbody>
<tr>
<td></td>
<td>NS</td>
<td>NS</td>
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</tbody>
</table>

three times the odds of having a fertility discussion with their oncologists. To my knowledge, this is the first study that distinguishes the differences between oncologist-initiated versus patient-initiated fertility discussions in statistical analyses.

In the second inquiry of cancer patients who had a fertility discussion with their oncologists (n=143), five factors were found to be significantly associated with having a fertility preservation consultation with a fertility specialist (Table 14). These factors consisted of whether the women had cancer between the ages of 25 and 34, received gonadotoxic cancer treatment with known threats to fertility, were childless at the time of cancer diagnosis, had a high level of fertility concern prior to commencing cancer treatment, and were satisfied with how their oncologists handled the fertility discussions. To my knowledge, no study has reported a link between patient satisfaction with how their oncologists handled the fertility discussions and subsequent consultation with a fertility specialist.
Table 14: Factors associated with receiving a fertility preservation consultation (n=143, 94 versus 49).

<table>
<thead>
<tr>
<th>Block 1: Socio-demographics at diagnosis</th>
<th>Bivariate analysis $\chi^2$</th>
<th>Multivariate logistic regression model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (between 25-29 &amp; 30-34)</td>
<td>p&lt;.05</td>
<td>OR 5.3 (1.04 to 27.04), p&lt;.05</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6.55 (1.17 to 36.81), p&lt;.05</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Place of residence</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Had a university degree</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Individual income &gt; $30,000</td>
<td>p&lt;.05</td>
<td>NS</td>
</tr>
<tr>
<td>Had no children</td>
<td>p&lt;.05</td>
<td>OR 4.28 (95% CI: 1.45 to 12.62), p&lt;.01</td>
</tr>
<tr>
<td>Had a partner</td>
<td>NS</td>
<td>NS</td>
</tr>
</tbody>
</table>

| Block 2: Cancer profiles               |                             |                                     |
| Years since cancer diagnosis           | p<.05                       | NS                                  |
| Breast cancer                          | p<.049                      | NS                                  |
| Received gonadotoxic cancer treatment  | p<.05                       | OR 7.04 (95% CI: 1.77 to 28), p<.01 |

| Block 3: Fertility concern at diagnosis|                             |                                     |
| Had a high level of fertility concern  | p=.05                       | OR 4.32 (96% CI: 1.21 to 15.41), p<.05 |

| Block 4: Perceived quality of fertility discussion with oncologists |                             |                                     |
| Who initiated the fertility discussion | NS                          | NS                                  |
| Level of satisfaction with fertility discussion | NS                          | OR 3.06 (95% CI: 1.07 to 8.73), p<.05 |

The findings of the second inquiry have concurred with two recent studies that cancer patients who were younger and did not have children at diagnosis were more likely to consult with a fertility specialist (Goodman et al., 2012; Letourneau et al., 2012a). However, we did not find the patients’ relationship status at the time of diagnosis was a significant predictive factor – a finding also confirmed by Letourneau and colleagues (2012b) in a large scale US survey of 918 young...
female cancer survivors. Furthermore, we found that cancer patients who had at least one child already at diagnosis had lower odds of receiving a consultation compared with others who were childless. Similarly, prior studies found that cancer patients who had children already at diagnosis (Goodman et al., 2012; Niemasik et al., 2012; Yee et al., 2012a) as well as those who were uncertain about their future childbearing plans (Duffy et al., 2005) were less likely to receive fertility information from their health providers and were less likely to receive a fertility preservation referral. Plausible reasons for this finding will be elaborated below.

In the third inquiry of those cancer patients who were referred to a fertility specialist for a fertility preservation consultation (n=49), no significant differences were found in regard to age, ethnicity, relationship status, education, income, and cancer history between women who chose to, or not to, pursue fertility preservation (Table 15). Previous studies found that patient relationship status was influential in fertility preservation decisions (Hill et al., 2012; Letourneau et al., 2012a). In contrast, we did not find the participant relationship status was significantly associated with the uptake of cryopreservation. On the other hand, we found that almost all participants who undertook fertility preservation did not have children, a finding contradicted by a Canadian survey study where they found parenthood status was not significantly associated with their participants’ fertility preservation decision (Hill et al., 2012).

In the logistic regression analysis of the third inquiry, the two factors that were found to be significantly associated with increased odds of the uptake of a fertility preservation procedure were whether patients had a high fertility concern at the time of the cancer diagnosis and whether patients perceived that their oncologists were supportive of their fertility preservation plans. Our findings show that participants who chose to proceed with fertility preservation were more likely to be satisfied with how their oncologists handled the fertility discussions and were likely to find their oncologists supportive of their cryopreservation plan. Furthermore, those who felt supported by their oncologists regarding their fertility preservation plans had lower post-treatment decision regret and more confidence that their decision was an informed choice compared to other women who perceived their oncologists as either neutral or non-supportive of their plan. This confirms
other recent reports that cancer survivors who consulted a fertility specialist had lower levels of decision regret and decisional conflicts, in comparison to those who did not receive a consultation and were unaware of their cryopreservation options prior to commencing cancer treatments (Bastings et al., 2014a; Letourneau et al., 2012a; Mersereau & Sandbulte, 2013).

Table 15: Factors associated with the uptake of fertility preservation procedure (n=49, 32 versus 17).

<table>
<thead>
<tr>
<th>Socio-demographics at diagnosis</th>
<th>Bivariate analysis $\chi^2$</th>
<th>Multivariate logistic regression model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (between 25-29 &amp; 30-34)</td>
<td>NS</td>
<td>--</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>NS</td>
<td>--</td>
</tr>
<tr>
<td>Place of residence</td>
<td>NS</td>
<td>--</td>
</tr>
<tr>
<td>Had a university degree</td>
<td>NS</td>
<td>--</td>
</tr>
<tr>
<td>Individual income &gt; $30,000</td>
<td>NS</td>
<td>--</td>
</tr>
<tr>
<td>Had no children</td>
<td>p&lt;.05</td>
<td>NS</td>
</tr>
<tr>
<td>Had a partner</td>
<td>NS</td>
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<thead>
<tr>
<th>Cancer profiles</th>
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</thead>
<tbody>
<tr>
<td>Years since cancer diagnosis</td>
<td>NS</td>
<td>--</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>NS</td>
<td>--</td>
</tr>
<tr>
<td>Received gonadotoxic cancer treatment</td>
<td>NS</td>
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</table>

| Level of fertility concern at diagnosis | NS | OR 5.61 (95% CI: 1.44 to 21.92), p<.05 |

<table>
<thead>
<tr>
<th>Perceived quality of fertility discussion with oncologists</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Who initiated the fertility discussion</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Level of satisfaction with fertility discussion</td>
<td>p&lt;.05</td>
<td>NS</td>
</tr>
<tr>
<td>Perceived support from oncologists of their FP plan</td>
<td>p&lt;.05</td>
<td>OR 7.21 (95% CI: 1.01 to 51.56), p&lt;.05</td>
</tr>
</tbody>
</table>

In summary, the current study found that having a high fertility concern at the time of cancer diagnosis was a significant determinant associated with young women’s receipt of fertility discussion and fertility preservation services across all three service levels. These include having a discussion with their oncologists about the potential fertility risks associated with their cancer treatment.
treatment, consulting with a fertility specialist about their pre-cancer treatment fertility preservation options, and proceeding with a cryopreservation procedure.

5.2 Validation of theoretical framework

Young women who have not yet completed their family at the time of receiving a cancer diagnosis are faced with very challenging decisions. They are dealing with a life threatening cancer diagnosis in addition to the possibility that the life-saving cancer treatments may have a negative impact on their future fertility (Crawshaw et al., 2013b; Halliday & Boughton, 2010; Hershberger et al., 2013). The narrow window of time in fertility preservation decision-making usually coincides with the emotional turmoil of receiving a cancer diagnosis and dealing with the uncertainty of cancer prognosis (Gardino & Emanuel, 2010; Mersereau, 2012). The findings of this study provide insights into understanding the process by which cancer patients make timely and important fertility preservation decisions under stress, as well as the factors associated with the receipt of fertility-related services at three important decision making points (Figure 4). These include fertility discussion, fertility preservation consultation, and the uptake of fertility preservation procedure. Furthermore, the findings of this study provide evidence to validate the new Integrated Fertility Preservation Decision-Making Framework developed in my comprehensive paper (Yee, 2011).

5.2.1 Fertility discussion

Contrary to the hypotheses of this synthesis framework, this study found that participants’ socio-demographic characteristics in Stage 1 were not significantly associated with the reception of a fertility discussion with their oncologists in Stage 2. As half of the fertility discussions were initiated by cancer patients, it is quite likely that many of these fertility discussions would not have occurred if patients did not take the initiative to inquire about fertility information (Shimizu et al., 2013; Quinn & Vadaparampil, 2009).
Figure 4: Factors associated with three critical points in the Integrated Fertility Preservation Decision-Making Framework

1. Between the ages of 25 and 34 (OR 5.3-6.55, p<.05)
2. Childless (OR 4.28, p<.01)
3. Received gonadotoxic cancer treatment (OR 7.04, p<.01)
4. High level of fertility concern (OR 4.32, p<.05)
5. Satisfied fertility discussion with oncologist (OR 3.06, p<.05)

1. High level of fertility concern (OR 5.61, p<.05)
2. Perceived having the support from oncologist of FP decision (OR 7.21, p<.05)

1. Perceived severity
2. Perceived personal susceptibility
3. Perceived benefits
4. Perceived barriers
5. Cue for action from oncologists

Fertility preservation attitudes and knowledge

Paper 1: Having a fertility discussion
- Medical consultation with oncologists
- Personalized medical information
- Awareness of cancer treatment
- Self-in-situation fertility risk appraisal

Paper 2: Receiving a FP consultation
- Primary appraisal
- Secondary appraisal
- Seeing a fertility specialist for consultation
- Fertility preservation option appraisal

Paper 3: Making a FP decision
- Informed fertility preservation decision
- Proceed
- Not to proceed

1. High level of fertility concern
(OR 5.22 p<.001)

Cancer profile
Treatment decision making styles
Socio-demographic characteristics
Findings of this study also support that certain patient characteristics in Stage 1, such as being proactive and assertive in requesting medical information, are influential in the receipt of fertility discussion in Stage 2. Our findings suggest that some oncologists may use their personal value judgments to determine their patients’ fertility interests. These biases and value judgments could hinder equity of access to fertility information and services for cancer patients. These findings parallel other reports that suggest assertive patients who have some prior fertility knowledge may have a better chance of receiving fertility information from oncologists (Geue et al., 2014; Kirkman et al., 2014); women who are passive may not receive essential information if they do not bring up the topic themselves (Garvelink et al., 2013). Further studies need to be conducted to investigate the association between certain patient characteristics (e.g. proactive, assertive, and passive) and treatment-decision making styles (e.g. active, collaborative, or passive) with the likelihood of being counselled by oncologists on fertility matters during cancer care. The findings would help to inform the development of effective fertility communication tools to assist oncologists in initiating fertility discussion with young patients routinely without their prompting.

The two factors associated with having a fertility discussion with an oncologist were year of cancer diagnosis and level of fertility concern at the time of cancer diagnosis. It is encouraging to find a positive shift in practice behaviors among Canadian oncologists to initiate a fertility discussion with cancer patients routinely since the release of fertility preservation practice guidelines by the American Society of Clinical Oncology in 2006. Future research should consider the use of prospective designs to observe if there is any further improvement in fertility discussion rates among Canadian oncologists.

5.2.2 Fertility preservation consultation

Previous studies have suggested that certain socio-demographic characteristics, patient factors, and cancer profiles are associated with the increased likelihood of fertility preservation referrals (Goodman et al., 2012; S. Lee et al., 2011). Findings from this study confirm that certain participants’ socio-demographic characteristics and cancer profiles in Stage 1 were significant in influencing the receipt of a consultation with a fertility specialist in Stage 4. Significant socio-demographic characteristics include whether the participants had cancer between the ages 25 and
34, and whether they were childless prior to their cancer treatment; significant cancer profiles include whether their cancer treatments were gonadotoxic with known threats to fertility, and whether they had a high level of fertility concern prior to commencing cancer treatment.

In addition, a link was found between patient satisfaction with how their oncologists handled the fertility discussions in Stage 2 and subsequent consultations with a fertility specialist in Stage 4. Studies found that deficiencies in oncologist-patient communications on fertility preservation matters, including ambiguity and lack of clarity in fertility answers received from oncologists could negatively impact patient experience, confidence, and satisfaction with cancer care (Corney & Swinglehurst, 2014; S. Lee et al., 2011; Niemasik et al., 2012; Peddie et al., 2012). A proactive approach of oncologists in the provision of fertility preservation resources, including making timely fertility preservation referrals, would enhance patient satisfaction in the quality of cancer care (Bastings et al., 2014). Effective training programs are needed to equip oncologists to make fertility discussion an integral part of cancer care for young women so as to facilitate timely referrals to fertility experts.

5.2.3 Uptake of fertility preservation procedure

Stage 5 of the Decision-Making Framework hypothesizes that the decision-maker has to contextually appraise the severity of the potential threat to fertility, as well as the perceived benefits and barriers of proceeding with the recommended fertility preservation option. With the majority of our survey participants reporting that they had a lot of time pressure, uncertainty, and stress during the decision-making process, our findings support the hypothesis that making a decision regarding fertility preservation while dealing with a life threatening cancer diagnosis is an inherently stressful decision. Furthermore, an association was found between having a high level of fertility concern at the time of the cancer diagnosis (i.e. the cancer profiles in Stage 1) and the treatment decision of proceeding with a fertility preservation procedure in Stage 5. In addition, we found that participants who chose to proceed with fertility preservation were more likely to be satisfied with how their oncologists handled the fertility discussions and were likely to find their oncologists supportive of their fertility preservation plan. Thus, the perception that their
oncologists were supportive of their fertility preservation plans served as a cue for action to proceed with a cryopreservation procedure.

Previous studies suggest that certain patient factors and socio-demographic characteristics are influential in fertility preservation decision-making. These include childlessness at diagnosis (Kim et al., 2013), relationship status (Hill et al., 2012; Letourneau et al., 2012), having a strong desire for future children (Kim et al., 2013b), and having high levels of fertility concern (Letourneau et al., 2012). In this study, we found no significant differences between women who chose to preserve fertility or not to take action following the consultation in regard to their age, ethnicity, relationship status, education, income, and cancer history. On the other hand, almost all participants who proceeded with fertility preservation were childless, a finding contradicted by a Canadian survey study where they found parenthood status was not significantly associated with their participants’ fertility preservation decision (Hill et al., 2012).

In this study, the majority of women reported having an enormous amount of stress and time pressure during the time when a fertility decision needed to be made. Heightened stress and constrained time in decision-making can interfere with a person’s ability to think clearly, process information efficiently, and make rational judgments that are geared to her personal values (Geue et al., 2014; Kim et al., 2013). Studies surveying breast cancer patients found that 32% reported having high levels of anxiety during the decision-making process (Peate et al., 2011); 39% expressed having difficulties in making a fertility preservation decision due to the time pressure (Hill et al., 2012). Another US study found that women who declined fertility preservation were more likely to be in a state of shock upon learning their cancer diagnosis and did not have the emotional strength to undergo a fertility preservation procedure (Klock et al., 2010). These reports, as with our findings, confirm the importance of the provision of mental health services to support cancer patients during the decision-making process (Hill et al., 2012). Furthermore, our findings provide important data to inform the development of future decision-making tools for fertility preservation (Peate et al., 2011). Research is also urgently needed to examine the effectiveness of using different decision aids in improving the quality of cancer patient decision-making capacity on fertility preservation (Garvelink et al., 2013; Peate et al., 2011).
The latest Canadian statistics report that one in five Canadians identify themselves as a member of a visible minority group (Statistics Canada, 2014), however, 87% of the participants in this study self-identified themselves as a Caucasian and 91% indicated that they were Canadian born. Furthermore, 97.3% of the participants were heterosexual. Research data on the fertility needs of cancer patients from minority groups and their experiences of how their fertility concerns were addressed by oncology care providers are extremely limited (Letourneau et al., 2012b; Vadaparampil et al., 2012). A recent UK qualitative study with 33 medical and psychosocial care providers found that practitioners lacked understanding of the lived experiences of their cancer patients from minority groups despite their commitment to provide sensitive care (Atkin, Chattoo, & Crawshaw, 2014). Fertility preservation involves the use of assisted reproductive technologies to harvest eggs for egg freezing, or fertilizing the eggs with partner sperm or donor sperm for embryo freezing. It is possible that fertility preservation decision-making factors vary by ethnicity, socio-economic backgrounds, immigration status, sexual orientation, religious and cultural backgrounds due to differences in health beliefs and help seeking behaviours (Hudson, 2012).

With the low representation of non-White women, sexual minority groups, and immigrants in this study, future work should use a more diverse patient sample to validate the new decision-making framework. Using a more diverse sample to replicate the current study would also increase the generalizability of the findings to cancer patients. Finally, two patient surveys have found gender differences in the receipt of cancer-related fertility information and fertility preservation services (Armuand et al., 2012; Mancini, et al., 2008), suggesting that oncology health providers are more attentive to the fertility needs of males than females, and are more comfortable in recommending sperm banking to males than egg and embryo freezing to females. Cancer patients of both genders should have equal chances of receiving fertility preservation services to optimize their reproductive potential. The receipt of fertility information and services should not be contingent on patient gender. Further studies are needed to explore how patient gender plays a role in influencing oncologist decisions in the provision of fertility care as well as patient decisions in pursuing fertility preservation prior to commencing cancer treatment.
5.3 Clinical practice guidelines

One of the key findings of the current study was that women who received a cancer diagnosis after the American Society of Clinical Oncology published their clinical practice guidelines on fertility preservation in 2006 had more than three times the odds of having a fertility discussion with their oncologists. In comparison to those diagnosed with cancer between 2000 and 2006, a positive shift in practice behaviors was evident with 42% of cancer patients receiving oncologist-initiated fertility discussion since 2006 compared with only 13% of women who had cancer prior. Unfortunately, there are no practice guidelines issued by Canadian oncology medical bodies and cancer societies to standardize the integration of fertility services into cancer care on national, provincial, and/or regional levels (Ronn and Holzer, 2013; Yee et al., 2013). The availability of Canadian practice guidelines geared to the provincial health care settings is important in avoiding ambiguity relating to the role and clinical responsibilities of oncologists and oncology practitioners in providing fertility care to cancer patients (Kelvin & Reinecke, 2012; Treves et al., 2011). Interventions at both the institutional and the policy levels are essential to integrate fertility services into the provincial and regional cancer systems so that all young women with cancer have equal opportunity to receive fertility information and fertility preservation services (Nisker, 2009, 2013).

To fill this gap, in 2014 the Canadian Fertility and Andrology Society has published evidence-based clinical practice guidelines on “Fertility Preservation in Reproductive Aged Woman Facing Gonadotoxic Treatments” from the perspective of reproductive medicine (CFAS, 2014). Institutional endorsements by cancer societies and oncology medical bodies of these practice guidelines could enhance oncologist confidence in the efficacy and safety of fertility preservation techniques so as to improve their likelihood of referring cancer patients to fertility clinics for consultation (Ethics Committee of ASRM 2013; Loren et al., 2013). Future intervention strategies should focus on how to raise cancer patient awareness of fertility issues through targeted interventions and awareness campaigns (Canada & Schover, 2005; Ronn & Holzer, 2013).
5.4 Patient educational materials

The Integrated Decision-Making Framework developed in this dissertation hypothesizes that cancer patient awareness of the potential fertility risks associated with cancer treatments is highly dependent on the availability and accessibility of reliable fertility educational materials published by credible cancer organizations (Quinn et al., 2012). The American Society of Clinical Oncology has published several patient brochures and leaflets on fertility preservation that are accessible via the Internet. Reliable educational materials on fertility preservation are also available from non-profit Canadian cancer groups, such as Cancer Knowledge Network and Fertile Future. Despite that, previous Canadian surveys found that cancer patients encountered significant barriers to timely accessing of educational materials related to fertility and fertility preservation options (Hill et al., 2012; Yee et al., 2012a). Using the unanalyzed questions in the current survey of patient experiences in searching for timely fertility resources and their appraisal of the quality of the obtained information, I hope in future work to identify barriers encountered by Canadian cancer patients to accessing reliable resources.

Oncologists are usually pressed for time in medical appointments because of the multiple medical issues that need to be discussed with cancer patients at the time of diagnosis. The provision of patient educational materials to supplement the fertility discussion would enhance patient capacity to comprehend the fertility information (Quinn et al., 2007; Redig et al., 2011; Yee et al., 2012a). It is hoped that increased awareness of patient educational resources in fertility preservation within the oncology community would encourage oncologists to consistently initiate a fertility discussion with all young female cancer patients (Louwé, et al., 2009; Quinn et al., 2008).

5.5 Oncologist-patient communications

Previous research suggests that the relative rarity of oncologist-initiated fertility discussions could be due to oncologists’ deficient knowledge regarding the availability of fertility

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5 [https://cancerkn.com/oncofertility-referral-network/](https://cancerkn.com/oncofertility-referral-network/)
6 [http://fertilefuture.ca/](http://fertilefuture.ca/)
preservation resources for cancer patients (Duffy et al., 2012; Quinn et al., 2007; Yee et al., 2012d). It is probable that oncologists are less likely to recommend fertility preservation options to their patients if they are uncertain about the availability of oncology cryopreservation services in their regions, if they do not know where to refer cancer patients, or if they assume that the referral waiting time will cause significant delay in commencing cancer treatment (Kelvin & Reinecke, 2012; Quinn et al., 2008).

Our recent survey of oncologists practicing in Ontario found that there was significant variation in attitudes, knowledge, and referral patterns for fertility preservation services (Yee et al., 2012d). The frequency of initiating a referral was strongly associated with knowing where to refer patients. In that study’s sample, about 45% of the surveyed 152 oncologists did not know where to refer their female cancer patients, and 69.7% rarely made a fertility preservation consultation referral. Another national survey of fertility clinics and in-vitro fertilization centres on the provision of fertility preservation services to young cancer patients reported very few referrals from oncology practitioners despite the availability of expedited services for cancer patients to receive a fertility preservation consultation (Yee et al., 2012b). Findings from these two prior surveys suggest that cancer patients are severely underserved by Canadian fertility clinics; oncology fertility preservation programs are underutilized by cancer patients despite their availability (Yee et al., 2012b; Yee et al., 2012d). The findings of this study, as with other Canadian studies, indicate opportunities for interventions on both the institutional and the service provider level to ensure that the fertility needs of young cancer patients are met by the cancer system (Hill et al., 2012; Yee et al., 2012a).

One of the desired outcomes of a successful fertility intervention in oncology care is that the fertility needs of all young patients are addressed appropriately (Loren et al., 2012; Practice Committee of ASRM, 2013). Every young patient should be informed by their oncologists shortly after a cancer diagnosis is made about the fertility risks associated with their cancer treatment in order to afford them ample time to make an informed decision regarding pursuing fertility preservation (Woodruff et al., 2014). The fertility needs of cancer patients may be overlooked if patients neither initiate the discussion with their oncology health providers nor ask for information.
(Garvelink et al., 2013). It is important to remember that cancer patients are usually under considerable stress at the time when a life-threatening cancer diagnosis is received. It is therefore unreasonable to expect patients to initiate the fertility discussion with their oncologists in order to obtain essential fertility information (Duffy et al., 2005; Gorman et al., 2012).

Oncologists play an essential role in communicating with cancer patients the potential treatment-induced fertility risks through the provision of personalized medical information (Brundage, 2010; Parker, Davison, Tishelman, & Brundage, 2005). Since having a fertility discussion with their cancer patients is the only way for oncologists to accurately assess their patients’ fertility concerns and future family building plans, it is crucial for oncologists to provide all necessary medical information related to cancer treatments, including the possibility that cancer treatments may impair fertility (Corney & Swinglehurst, 2014; Niemasik et al., 2012; Wright, Coad, Morgan, Stark, & Cable, 2014). As oncologists choose what information to discuss during medical appointments, it is plausible that the oncologists who initiated the fertility discussion with their cancer patients were better prepared to handle their patients’ queries on fertility matters and had the resources ready to refer concerned individuals to a fertility center for pre-cancer treatment cryopreservation consultation in comparison with oncologists who only addressed fertility preservation issues after patient prompting (Mersereau, 2012; Yee et al., 2012c; Yee et al., 2012d). Future studies should focus on evaluating the effectiveness of different training models in influencing oncology providers’ attitudes and knowledge in the provision of fertility care to cancer patients. The applicability of using various fertility preservation clinical tools, such as decision aids, prompt sheets and clinical guidelines, to facilitate physician-patient communications under different clinical scenarios should be tested.

The findings of this research demonstrate that oncologists play a pivotal role in the provision of fertility information and resources to young cancer patients at the time of their diagnosis. These findings also confirm that it is important for oncologists to be proactive in initiating a fertility discussion with all newly diagnosed cancer patients regardless of their income level and relationship status, and that they provide comprehensive and helpful information on fertility risks and options in a timely manner (S. Lee et al., 2011; Ronn & Holzer, 2013). Such timely
and proactive service provision is essential to support cancer patients to make high quality fertility preservation decisions alongside avoiding unnecessary life-threatening delays in cancer treatment. Future prospective studies are needed to confirm the causal nature of the association between the quality of fertility discussion with oncologists and patient confidence in making an informed and satisfactory fertility preservation decision. The findings would be useful in informing the development of effective intervention strategies to shift the practice cultures and behaviors of oncologists related to fertility preservation (Blough, Mansfield, & Kondapalli, 2014).

5.6 Implications for social work practice

In keeping with the fundamental principle of equity of access to medical information, all young cancer patients of childbearing age should have an equal opportunity to receive essential medical information concerning their reproductive health and to make their own decision regarding the receipt of fertility preservation services (Figure 5). Information related to fertility risks associated with their cancer treatment should not be withheld (Crawshaw, 2013a; Nisker, 2009, 2013; Woodruff et al., 2014). A proactive approach to addressing the fertility needs of young cancer patients, including the provision of both oral and written fertility resources and timely referrals to fertility specialists, would probably enhance patient satisfaction with the quality of cancer care (Crawshaw et al., 2009; Murphy, Sawczyn, & Quinn, 2012).

In oncology programs where fertility preservation services have yet to be integrated into the model of care, social workers can collaborate with other disciplines to develop clinical tools such as discussion prompts, clinical check-lists, decision aids, and patient resource packages to standardize the provision of fertility care (Murphy et al., 2012; Quinn et al., 2012). The involvement of social workers in developing robust liaison systems with fertility centres and fertility preservation referral protocols in oncology departments could help to eliminate systemic barriers for young women in accessing timely fertility services in cancer care (Redig et al., 2011; Treves et al., 2011; Woodruff, 2008).
Figure 5: Ideal Fertility Preservation Decision-Making Model

1. Perceived severity
2. Perceived personal susceptibility
3. Perceived benefits
4. Perceived barriers
5. Cue for action from oncologists
Findings of this study are very relevant to social work practitioners who work in multi-disciplinary oncology and assisted reproduction settings, as well as in individual and family services related to direct practice, family planning, and reproductive health (Gardino et al., 2010; Kelvin & Reinecke, 2012). Fertility preservation in oncology is an emerging area that requires partnerships involving health providers in the areas of both oncology and reproductive medicine (Woodruff, 2010). In oncology practice settings, social workers can act as fertility preservation navigators or liaisons in clinical care in order to follow through with the care plan initiated by oncologists (Elizur et al., 2009; King et al., 2008; Zebrack et al., 2007). Their roles could include that of providing psychosocial care to patients and their partners who have fertility concerns, making expeditious referrals to fertility preservation programs which have experience in dealing with cancer patients, and being the liaison between the oncology and fertility preservation teams for greater integration of care across these health care settings. Of considerable importance is the social work practitioners’ role in advocating for passive cancer patients. Social workers can help cancer patients access essential fertility resources and services, such as assisting them in applying financial subsidies for fertility preservation procedures provided by non-profit organizations, and informing them about government tax credits (King et al., 2008; Zebrack & Walsh-Burke, 2004). As Canada and Schover (2005) highlight that it is important to integrate a firm evidence-based practice model into the provision of better patient education and client-centered reproductive care. Clinical skills of social workers are essential to support patients during their fertility preservation decision-making process when a treatment decision needs to be made under stress and time pressure (Canada and Schover, 2005; de Ziegler et al., 2010; Redig et al., 2011; Zebrack et al., 2004).

5.7 Strengths and limitations

This study has several limitations. The cross-sectional survey design limits one’s ability to determine causality. We are unable to derive definitive conclusions regarding statistical relationships between observed variables. The sampling group was comprised of women who had completed cancer treatments and survived cancer, making their retrospective accounts of how fertility matters were addressed when they received cancer care potentially subject to recall bias.
There is a possibility of coverage error as women with low computer literacy and less English proficiency may have chosen not to complete the online survey. There is a potential sampling bias because the majority of participants were recruited from cancer organizations and therefore might be more informed about fertility resources and services. Furthermore, cancer survivors who opted to participate in this study in response to the recruitment survey flyer may have had more personal interest in the research topic related of cancer and fertility, and if so, these personal interests may have led to greater extremes in reported satisfaction or dissatisfaction with how their oncologists handled their fertility concerns during cancer care, as well as more positive or negative feelings towards their fertility preservation decision made at the time of cancer diagnosis. Finally, the majority of our survey participants were Caucasians, which limits the generalizability of the findings to other ethnic groups.

Despite these limitations, this is the first Canadian study that used a national community sample to investigate the prevalence of young cancer patients in receiving fertility preservation services. A key strength of this study is the geographically diverse sample of young cancer survivors from different provinces. The participants were recruited through the help of 53 institutions and cancer groups across Canada. Social media and other digital channels were used to reach out to cancer survivors who may not have otherwise been reached. In addition, all women in this study were in their prime years of childbearing at cancer diagnosis, and four in five had cancer treatments with known threats to fertility. Our sample includes a mixture of young women with different cancer diagnoses instead of using a specific patient group, such as breast cancer patients who are over-represented in fertility research (Duffy et al., 2005; Gorman et al., 2010; R. J. Lee et al., 2011; Partridge et al., 2004).

In conclusion, the findings from this large, national study provide novel information of the pivotal role by Canadian oncologists in initiating fertility discussions with cancer patients and making timely referrals for them to access fertility preservation services. The findings of this study show that oncologists play a pivotal role in the provision of fertility services in that they are not only gate keepers, knowledge brokers, and referral initiators of fertility preservation consultation, they are catalysts in supporting cancer patients make important fertility preservation decisions in
conjunction with the consultation provided by a fertility specialist. The findings are also very relevant to social work practitioners who work in multi-disciplinary health settings. Social workers can be a catalyst in promoting seamless access to essential fertility services through coordinating and collaborating with other health disciplines in delivering patient-centered care. Furthermore, social work practitioners can be involved in advocacy and program planning to eliminate systemic barriers for young cancer patients in accessing timely fertility preservation services.
References


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Appendix A
Research Ethics Approval in August 2012

PROTOCOL REFERENCE # 27879
August 10, 2012

Dr. Esme Fuller-Thomson
FACULTY OF SOCIAL WORK

Ms. Samantha Yee
FACULTY OF SOCIAL WORK

Dear Dr. Fuller-Thomson and Ms. Samantha Yee,

Re: Your research protocol entitled, "Cancer, fertility and motherhood: Addressing the fertility needs of young women with cancer in the context of stress, uncertainty, and time pressure"

ETHICS APPROVAL

Original Approval Date: August 10, 2012
Expiry Date: August 9, 2013
Continuing Review Level: 2

We are writing to advise you that the Health Sciences Research Ethics Board (REB) has granted approval to the above-named research protocol, for a period of one year. Ongoing research under this protocol must be renewed prior to the expiry date.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events in the research should be reported to the Office of Research Ethics as soon as possible.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your current ethics approval. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry.

If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

Judith Friedland, Ph.D.
REB Chair

Daniel Gyewu
REB Manager
Appendix B
Research Ethics Annual Review Approval in August 2013

PROTOCOL REFERENCE #: 27870
August 9, 2013

Dr. Esme Fuller-Thomson Ms. Samantha Yee
FACULTY OF SOCIAL WORK FACULTY OF SOCIAL WORK

Dear Dr. Fuller-Thomson and Ms. Samantha Yee,

Re: Your research protocol entitled, "Cancer, fertility and motherhood: Addressing the fertility needs of young women with cancer in the context of stress, uncertainty, and time pressure."

ETHICS APPROVAL
Original Approval Date: August 10, 2012
Expiry Date: August 9, 2014
Continuing Review Level: 2
Renewal: 1 of 4

We are writing to advise you that you have been granted annual renewal of ethics approval to the above-referenced research protocol through the Research Ethics Board (REB) full board review process. Please note that all protocols involving ongoing data collection or interaction with human participants are subject to re-evaluation after 5 years. Ongoing research under this protocol must be renewed prior to the expiry date.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your protocol. Note that annual renewals for protocols cannot be accepted more than 30 days prior to the date of expiry as per our guidelines.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible. If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

[Signatures]

Elizabeth Peter, Ph.D. Daniel Gyewu
REB Chair REB Manager
Appendix C
Research Ethics Annual Review Approval in August 2014

PROTOCOL Reference # 27879

July 25, 2014

Dr. Esme Fuller-Thomson
FACULTY OF SOCIAL WORK

Ms. Samantha Yee
FACULTY OF SOCIAL WORK

Dear Dr. Fuller-Thomson and Ms. Samantha Yee,

Re: Your research protocol entitled, "Cancer, fertility and motherhood: Addressing the fertility needs of young women with cancer in the context of stress, uncertainty, and time pressure"

ETHICS APPROVAL

| Original Approval Date: August 10, 2012 |
| Expiry Date: August 9, 2015 |
| Continuing Review Level: 2 |
| Renewal: Data Analysis Only |

We are writing to advise you that you have been granted annual renewal of ethics approval to the above-referenced research protocol through the Research Ethics Board (REB) delegated process. Please note that all protocols involving ongoing data collection or interaction with human participants are subject to re-evaluation after 5 years. Ongoing research under this protocol must be renewed prior to the expiry date.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your protocol. Note that annual renewals for protocols cannot be accepted more than 30 days prior to the date of expiry as per our guidelines.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible. If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

Elizabeth Peter, Ph.D.
REB Chair

Daniel Gyewu
REB Manager
Appendix D
Study Questionnaire

* Mandatory question

A) Your current demographics and health status

1. *What is your current age? _______

2. *What is your sexual orientation?  □ Heterosexual
                                            □ Same-sex
                                            □ Other

3. *What is your ethnic background? ________________

4. *Are you an immigrant?  □ No
                                            □ Yes, how many years have you been in Canada living in Canada _______

5. *What is your highest level of education?  □ Elementary, junior high, or less
                                            □ High school
                                            □ College or technical school
                                            □ Undergraduate
                                            □ Master’s degree
                                            □ Doctorate

6. *Do you have any religious background?
                                            □ None
                                            □ Anglican
                                            □ Buddhism
                                            □ Catholic
                                            □ Christianity
                                            □ Hinduism
                                            □ Islam
                                            □ Judaism
                                            □ Sikhism
                                            □ Other, please specify: ______________________________

7. *What is your current relationship status?
                                            □ Single, never married
                                            □ Married or partnered
                                            □ Separated or divorced
                                            □ Widowed

8. *Do you have any biological children?
                                            □ No children
                                            □ 1 child
9. *Do you want to have children?  [answer only if reply to Q8 is ‘no children’]
   - □ Never wanted children
   - □ Don’t want children now but did in the past
   - □ Not sure
   - □ Yes

10. *How would you rate your overall physical health?
    - □ Very poor
    - □ Poor
    - □ Fair
    - □ Good
    - □ Very good

11. *How would you rate your overall quality of life?
    - □ Very poor
    - □ Poor
    - □ Fair
    - □ Good
    - □ Very good

12. *What is your overall level of satisfaction with life on a scale from ‘1’ – not satisfied at all, to ‘5’ – very satisfied? ______

B) Your cancer history and demographics when diagnosed with cancer

13. *What was your cancer diagnosis?
    - □ Breast
    - □ Cervix
    - □ Gastrointestinal
    - □ Head and neck
    - □ Hodgkin lymphoma
    - □ Lung
    - □ Non-Hodgkin lymphoma
    - □ Pancreas
    - □ Sarcoma
    - □ Skin
    - □ Stomach
    - □ Thyroid
    - □ Uterus
    - □ Urologic (i.e. bladder, kidney)
    - □ Other, please specify: ___________________________ 
    - *At what stage? ______

14. *At what age were you diagnosed with cancer? ______

15. *What types of cancer treatments did you receive? (☑ check all that apply)
    - □ Surgery, please specify type: _____________________________________________
    - □ Chemotherapy
    - □ Radiation therapy
    - □ Stem cell transplantation
    - □ Others, please specify: _____________________________________________

16. *Please list all the oncologists involved in your cancer care: (☑ check all that apply)
    - □ Surgical oncologist
    - □ Medical oncologist
    - □ Radiation oncologist
    - □ Gynecologic oncologist
    - □ Others, please specify: _____________________________________________
17. *What was your relationship status at that time?*
   - [ ] Single, never married
   - [ ] Married or partnered
   - [ ] Separated or divorced
   - [ ] Widowed

18. *What was your annual income level (before tax) at that time?*
   - [ ] Less than $30,000
   - [ ] Between $30,001 and $50,000
   - [ ] Between $50,001 and $70,000
   - [ ] Between $70,001 and $90,000
   - [ ] Between $90,001 and $110,000
   - [ ] Over $110,001

19. *Where did you live at that time?*
   - [ ] British Columbia
   - [ ] Alberta
   - [ ] Saskatchewan
   - [ ] Manitoba
   - [ ] Ontario
   - [ ] Quebec
   - [ ] New Brunswick
   - [ ] Nova Scotia
   - [ ] Prince Edward Island
   - [ ] Newfoundland and Labrador
   - [ ] Northwest Territories
   - [ ] Yukon
   - [ ] Nunavut

20. *How would you describe your place of residence at that time?*
   - [ ] Metropolitan area
   - [ ] Major town
   - [ ] Urban city
   - [ ] Rural area

C) Your motherhood status and parenthood desire

21. *Did you have any biological children at the time of cancer diagnosis? [skip if your reply to Q8 is ‘no children’]*
   - [ ] No children
   - [ ] 1 child
   - [ ] 2 children
   - [ ] 3 or more children

22. *Had you completed your family at that time? [skip if your reply to Q8 is ‘no children’]*
   - [ ] No
   - [ ] Yes

23. *How would you rank your desire to be a mother on a scale from ‘1’ (no desire) to ‘4’ (strong desire)?*
   - [ ]

24. *Have you ever tried to have children after completing the cancer treatment?*
   - [ ] I have decided not to have (more) children
   - [ ] I am not yet ready to have (more) children
   - [ ] I am planning to try soon
   - [ ] I am actively trying to conceive now
   - [ ] I have tried but was not able to conceive
   - [ ] I am actively trying to conceive
   - [ ] I am pregnant now
I have had at least one child conceived after completing my cancer treatment

25. *To what extent has your cancer experience changed your desire to pursue motherhood?
- It has significantly decreased my desire to pursue motherhood
- It has slightly decreased my desire to pursue motherhood
- No difference
- It has slightly increased my desire to pursue motherhood
- It has significantly increased my desire to pursue motherhood

26. *To what extent has your cancer experience changed your parenting? [skip if your reply to Q8 is ‘no children’]
- It has made me a much worse parent
- It has made me a slightly worse parent
- No difference
- It has made me a slightly better parent
- It has made me a much better parent

27. *Have you ever received any assisted reproductive services post cancer treatment?
- Never
- Yes, I only received consultation from a fertility doctor
- Yes, I received assisted reproductive treatments. Please specify: __________________________

28. *How would you describe your current fertility status?
- I am as fertile as other women of my age
- I am less fertile as other women of my age
- I am not certain about my fertility status

29. *How often do you think about your fertility from ‘1’ (not at all) to ‘5’ (very often)?_______

30. Can you tell us what comes to your mind when you think about fertility? _____________________

31. *As a female, how strongly do you associate fertility with each of the following domains on a scale from ‘1’ (no association) to ‘5’ (extremely strong association)?
- My self-identity as a person
- My sexual identity as a woman
- My overall reproductive health
- My reproductive capacity to have children
- My self confidence in developing satisfactory family relationships
- My self confidence in developing satisfactory social relationships
- My self confidence in developing satisfactory romantic relationships
- My self confidence in developing satisfactory partnered/married relationships
D) Fertility issues related to cancer care

32. *In each of the following items, how would you rank your level of concern at the time when you received cancer care on a scale from '1' (not concerned at all) to '5' (very concerned)?
   a. The potential side effect of cancer treatment on my physical appearance ______
   b. The potential side effect of cancer treatment on my overall reproductive health ______
   c. The potential side effect of cancer treatment on my capacity to have children ______

33. *In each of the following items, how would you rank your level of awareness at the time when you received cancer care on a scale from '1' (not aware at all) to '5' (very aware)?
   a. The potential side effect of cancer treatment on my reproductive health ______
   b. The potential side effect of cancer treatment on my capacity to have children ______
   c. The options to preserve fertility prior to cancer treatment ______
   d. The procedures involved in fertility preservation ______
   e. The costs involved in fertility preservation ______
   f. The timeframe involved in completing fertility preservation procedures ______

34. *Did you recall having a discussion with any of your doctors on fertility matters related to cancer? (check all that apply)
   - I could not remember if I had a discussion with any doctor [skip Q35-Q36 and go to Q37]
   - No, I had no discussion with any doctor [skip Q35-Q36 and go to Q37]
   - Yes, I had a discussion with my family doctor
   - Yes, I had a discussion with my surgical oncologist
   - Yes, I had a discussion with my medical oncologist
   - Yes, I had a discussion with my radiation oncologist
   - Yes, I had a discussion with my gynecologic oncologist
   - Yes, I had a discussion with others, please specify: ______________________________________

35. *How did the fertility discussion occur?
   - I initiated the discussion with my oncologist and asked for information
   - My oncologist initiated the discussion with me and provided me with information

36. How satisfied were you of how your doctors handled your fertility concerns during your cancer care on a scale from '1' – not satisfied at all, to '5' – completely satisfied? ______
   Can you tell us more of why you gave this ranking? __________________________________________
   _______________________________________________________
   _______________________________________________________

37. In retrospect, was there anything you wish your oncologist should have done differently in addressing your fertility concerns? __________________________________________
   _______________________________________________________
   _______________________________________________________
E) Information seeking of fertility resources

38. *How important was it for you to receive information relating to cancer and fertility at the time of diagnosis, on a scale from ‘1’ (not important) to ‘4’ (extremely important)? _______

39. *Had you ever tried to locate information relating to cancer and fertility at the time of diagnosis?
   - No [skip ahead to Section F]
   - Yes

40. *How did you locate the information? (check all that apply)
   - Through talking to my friends and family [skip ahead to Section F]
   - Through browsing the Internet
   - Through talking to health care providers, e.g. nurses and social workers [skip ahead to Section F]
   - Through contacting fertility clinics [skip ahead to Section F]
   - Through contacting cancer organizations and cancer patient groups [skip ahead to Section F]
   - Others, please specify: ________________________________ [skip ahead to Section F]

41. How was your experience when searching for fertility information through the Internet on a scale from 1 to 5, with ‘1’ - totally disagree, ‘2’ - disagree, ‘3’ - neutral, ‘4’ - agree, and ‘5’ - totally agree, or N/A?
   a. It was easy to find the information/resources: ______
   b. It was quick to find the information/resources: ______
   c. The information/resources were well organized and centralized: ______
   d. The information/resources were reliable: ______
   d. The information/resources were relevant to what I was looking for: ______

42. What were the main websites you used to search for fertility information related to cancer?
   ______________________________________________________
   ______________________________________________________

F) Referral for fertility consultation

43. *Did your doctor refer you to see a fertility specialist or to an IVF clinic for consultation about fertility preservation options?
   - No, I was not referred
   - Yes, I was referred by
     - My family doctor [skip ahead to Q46]
     - My surgeon [skip ahead to Q46]
     - My medical oncologist [skip ahead to Q46]
     - My radiation oncologist [skip ahead to Q46]
     - My gynecologic oncologist [skip ahead to Q46]
     - Others, please specify: ____________________________ [skip ahead to Q46]
44. If you were given an opportunity at that time, how much would you have liked your oncologist to make a referral, using a scale from 1 to 5 (‘1’ – definitely not, ‘2’ – probably not, ‘3’ – uncertain, ‘4’ – probably, ‘5’ – definitely)?  
Please elaborate: 

__________________________________________________________________________

__________________________________________________________________________

45. If you were given an opportunity at that time, how much would you have considered preserving your fertility through egg and embryo freezing using a scale from 1 to 5 (‘1’ – definitely not, ‘2’ – probably not, ‘3’ – uncertain, ‘4’ – probably, ‘5’ – definitely)? 
Please elaborate: 

__________________________________________________________________________

__________________________________________________________________________

46. *How long did you wait to get an appointment to see a fertility specialist?  
☐ Only a few days  
☐ A few days to a week  
☐ 1 to 2 weeks  
☐ 2 to 3 weeks  
☐ 3 to 4 weeks  
☐ More than a month

47. *What was the outcome of the medical consultation with a fertility specialist?  
☐ I was referred but did not attend the medical consultation [skip ahead to Section G]  
☐ I chose not to proceed with fertility preservation  
☐ I chose to freeze my eggs  
☐ I chose to freeze embryos using my partner’s sperm  
☐ I chose to freeze embryos using sperm from a sperm bank  
☐ Other, please specify: ______________________________ 

48. How much was your oncologist supportive of your fertility preservation decision on a scale ‘1’ (completely non-supportive) to ‘5’ (extremely supportive)? 
Please elaborate: 

__________________________________________________________________________

__________________________________________________________________________

49. Can you tell us more about your experience with the fertility specialist and/or the fertility clinic?  

__________________________________________________________________________
50. *Have you returned to the fertility clinic to use your frozen eggs or embryos for pregnancy purpose? [only if the answer in Q47 is the third, the fourth or the fifth choice]

☐ No
☐ Yes, please specify the pregnancy outcome: ______________________________________
☐ No applicable

G) Decision-making in fertility preservation

51. The following categories represent five different decision-making styles commonly used by people when making important treatment decisions. Please sequentially rank each decision making style according to your personal preference, put ‘1’ as your most preferred style, and ‘5’ as your least preferred style⁷:

   _____ I prefer to make the decision about which treatment I will receive
   _____ I prefer to make the final decision about my treatment after seriously considering my doctor’s opinion
   _____ I prefer that my doctor and I share responsibility for deciding which treatment is best for me
   _____ I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion
   _____ I prefer to leave all decisions regarding treatment to my doctor

[Skip ahead to Section H if the answer to Q43 is ‘no, I was not referred’]

52. In each of the following questions, please evaluate the fertility preservation decision you had made on a scale from 1 – strongly disagree, and 5 – strongly agree⁸?

   a. I knew the pros and cons of fertility preservation ______
   b. I made a well-informed fertility preservation choice ______
   c. I was satisfied with the fertility preservation information I received ______
   d. I wanted clearer advice on preserving fertility ______
   e. I wanted more information about the decision to preserve fertility ______
   f. I was adequately informed about the different options to preserve fertility ______
   g. The decision I made was the best possible decision for me personally ______
   h. My decision was consistent with my personal values ______
   i. I had as much input as I wanted in the choice of preserving my fertility ______
   j. I am satisfied with the decision that was made about preserving my fertility ______
   k. It was the right decision ______
   l. I regret the decision that was made ______
   m. I would go for the same decision if I had to do it over again ______

⁷ A 5-item Control Preferences Scale (Degner et al., 1997)
⁸ The first 5 items are from the Informed Choice Subscale of the Treatment Decision Evaluation Scale (Stalmeier et al., 2005). The next 5 items are from the Satisfaction with Decision Scale (Holmes-Rovner, 1995). The original scale has 6 items but one item “I expect to successfully carry out (or continue to carry out) the decision I made” was removed because it is not relevant to the research topic. The last 5 items are from the Decisional Regret Scale (Brehaut et al., 2003). Words that are revised from the original instruments to better reflect the research topic are in italic.
n. The decision did me a lot of harm
o. The decision was a wise one

53. Reflecting on your psychological state at the time of diagnosis, to what degree did each of the following areas affect your ability to make a decision on fertility preservation, using a scale from ‘1’ (not at all) to ‘4’ (a lot)?
   a. Your stress level at that time?
   b. The time pressure at that time?
   c. Your sense of uncertainty at that time?

54. Is there anything you would like us to know regarding your psychological state at the time of diagnosis when you had to make a decision on fertility preservation?

________________________________________________________________________

________________________________________________________________________

H) Knowledge of cancer-related fertility matters and assisted reproductive services

55. *Please indicate whether the following statements are true or false. (✓) indicates the right answer

<table>
<thead>
<tr>
<th></th>
<th>True</th>
<th>False</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Cancer treatment such as chemotherapy and radiation can affect a woman’s fertility by reducing her reproductive capacity.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Cancer treatment has less impact on women who are younger in age than women who are more mature because of the resilience of reproductive organs among younger groups.</td>
<td></td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>c) It is not feasible for cancer patients to pursue fertility preservation prior to cancer treatment because of the time involvement in completing the procedure.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Similar to cancer treatments, the costs of preserving fertility for cancer patients are covered by universal health care across Canada because of their unique medical situation.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) The use of assisted reproductive treatment can help to restore a woman’s fertility and reproductive capacity.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) It is not advisable for single women to proceed with fertility preservation because they do not have a partner.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>g) The pregnancy success rates of using frozen eggs and frozen embryos are very similar nowadays because of technological and scientific advancements.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>h) Fertility rates start to decline when a woman turns 40.</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
i) Eggs and embryos can be frozen indefinitely and there is no maximum expiry date on storage. ✔

j) Preserving fertility prior to cancer treatment is highly recommended by oncology medical societies. ✔

### I) Coping and stress management

In each of the following statements, please indicate to what extent did it applied to you when you managed your cancer experience, using a scale from 1 to 4 (‘1’ – not used, ‘2’ – used somewhat, ‘3’ – used quite a bit, and ‘4’ – used a great deal)⁹:

56. I know what had to be done, so I doubled my efforts and tried harder to make things work _____
57. I came out of the experience better than when I went in _____
58. I made a plan of action and followed it _____
59. I just took things one step at a time _____
60. I stood my ground and fought for what I wanted _____
61. I came up with a couple of different solutions to the problem _____
62. I concentrated on something good that could come out of the whole thing _____
63. I changed or grew as a person in a good way _____
64. I blamed myself _____
65. I criticized or lectured myself _____
66. I thought about fantastic or unreal things that made me feel better _____
67. I hoped a miracle would happen _____
68. I wished I could change the way that I felt _____
69. I felt bad that I couldn’t avoid the problem _____
70. I tried to forget the whole thing _____

### J) Others

71. How did you hear about this survey study?
   - [ ] From a friend
   - [ ] From a family member
   - [ ] From a cancer organization
   - [ ] From a cancer patient network

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⁹ A 42-item Ways of Coping Checklist - Revision (Vitaliano et al., 1985) based on the 68-item Ways of Coping Checklist (Folkman and Lazarus, 1980). Only the problem-focused coping dimension (first 8 items) and self-blamed attribution and avoidance dimension (next 7 items) are used (Cousson-Gelie et al., 2010).
72. Is there anything you would like to comment on regarding this survey or the topics being studied?
__________________________________________________
__________________________________________________
__________________________________________________

THANK YOU very much for taking the time to complete the survey!

Please send us an email at goodluck.draw@gmail.com if you would like to participate in a draw conducted at the end of each month. Two winners will be selected to receive an Amazon gift certificate. Winners will be notified by email.

Please send an email to cancerfertility@gmail.com if you would like to know the correct answers in Section H: Knowledge of cancer-related fertility matters and assisted reproductive services.

Please use Google or Yahoo to create a new email address if you do not want to use your own personal email for contact purpose. Your email will be deleted after the monthly draw.
Appendix E
Participant Consent Form

You are invited to participate in an online survey that is designed to explore the views of female cancer survivors on fertility matters related to cancer care, and their perspective of using assisted reproductive technology to preserve eggs and embryos before cancer treatment.

There is no anticipated risk as a result of participating in the online survey. However, there is a possibility that some questions in the survey may trigger some negative emotions you might have regarding your current fertility status, and how your oncologists handled your fertility concerns (if any) during your cancer treatment.

There is no direct benefit for you to participate in the online survey. This research study aims to collect useful data to better understand how fertility matters are addressed by the Canadian cancer system. Therefore your participation may benefit other young women who are newly diagnosed with cancer in the future.

To participate in the online survey, you must meet all of the following criteria:

1) you are a female cancer survivor;
2) you received a cancer diagnosis after the year 2000;
3) you were between the ages of 18-39 when diagnosed with cancer;
4) you received cancer treatment in Canada; and
5) you have completed your active cancer treatment.

You will not be asked to provide your name in the online survey. You will not be asked to provide any personal information that may potentially disclose who you are. Your participation is completely anonymous. Whether or not you choose to participate in this study will not affect the services you receive. This survey will take approximately 30-45 minutes to complete.

Most questions will ask you to click either on a choice of categories or on a sliding scale. Some of these multiple choice and sliding scale questions are optional. Please feel free to skip the questions and go to the next one if you do not wish to answer any of these optional questions. Some questions are open-ended so that you can express your personal perspectives in your own written words. You can skip the open-ended questions if you do not want to answer any of them.

You have the right to terminate the online survey at any time before submission. Your participation is completely voluntary. However, once you click the “submit” button at the end of the survey, you will no longer be able to withdraw your data.
As a token of appreciation, five participants will be randomly selected at the end of each month during the data collection period to receive one of the five $20 Amazon gift certificates. Participation in the monthly draw is optional, and it is entirely up to you if you would like to provide your contact information in order to participate in the monthly draw. It is estimated that the chance of winning a prize in the monthly draw is approximately 10% (5 out of 50 survey respondents). The winners will be notified by email of the Amazon gift certificate coupon number. All the contact information will be discarded after each draw.

If you have any questions about this research study, please contact the Principal Investigator, Samantha Yee at sy.yee@utoronto.ca, or her doctoral thesis supervisor, Professor Esme Fuller-Thomson at emse.fuller.thomson@utoronto.ca. If you have questions regarding your rights as a research participant and the investigator’s responsibilities, etc., please contact the Office of Research Ethics of the University of Toronto at ethics.review@utoronto.ca.

CONSENT TO PARTICIPATE:

_____ I have read the consent form and I consent to participate in the study

_____ I have read the consent form and I do not consent to participate in the study
Appendix F
Online Survey’s Consent Form
(Print screen)

A research study on Cancer, Fertility and Motherhood

Thank you for your willingness to participate in this anonymous online survey that is designed to explore the retrospective views of female cancer survivors on fertility matters related to cancer care.

To participate in this survey study, you must meet the following criteria:

1. You are a female cancer survivor;
2. You received a cancer diagnosis after 2000
3. You were between the age of 18-39 when diagnosed with cancer;
4. You received cancer treatment in Canada; and
5. You have completed your cancer treatment.

The risks and benefits of participating in this survey study are posted on the research project website www.cancerandfertility.com

☐ Yes, I have read the consent form about the risks and benefits of participating in this survey study
☐ Yes, I am eligible to participate in this survey study
☐ Yes, I consent to participate in this survey study

Save and continue later >>
Appendix G
Research Project Website
(Print Screen)

("Cover" webpage)

("Home" webpage)

("About the Study" webpage)

("Research Committee" webpage)
Appendix G (Continue)

Research Project Website
(Print Screen)

(“Consent to Participate” webpage)

(“Start Online Survey” webpage)

(“Resources” webpage)

(“Contact us” webpage)
Appendix H
Social Media Project Accounts
(Print Screen)

(Facebook)

(Twitter)
Appendix I

Acknowledge List of Participating Cancer Organizations and Cancer Groups

1. Abreast of ‘bridge Cancer Survivor Dragon Boat Club Lethbridge Alberta
2. Bikinis for Breast Cancer
3. Bladder Cancer Canada
4. Bladder Cancer Support Group
5. Breast Cancer Action Kingston
8. Breast Cancer Support Network
9. Breast Cancer Support Services
10. Breast Friends Dragon Boat Racing Team Edmonton
11. British Columbia Cancer Agency
12. Canadian Breast Cancer Foundation
13. Canadian Cancer Society, North West Territories Division Alberta
14. Canadian Cancer Society, Nova Scotia Division
15. Canadian Cancer Survivor Network
16. Canadian Partnership Against Cancer
17. Canadian Skin Cancer Foundation
18. Cancer Care Manitoba
19. Cancer Care Nova Scotia
20. Cancer Chat Canada
21. Cancer Fight Club
22. Cancer Insight Ltd
23. Cancer Knowledge Network
24. Cancerview
25. Colorectal Cancer Association of Canada
26. Compassionate Beauty
27. David Cornfield Melanoma Fund
28. Ellicsr: Health, Wellness & Cancer Survivorship Centre
29. Gilda’s Club Great Toronto
Appendix I (Continue)

Acknowledge List of Participating Cancer Organizations and Cancer Groups

30. Gilda’s Club Simcoe Muskoka
31. Heart - Hope Eternal Areola Reconstructive Tattooing
32. Hearth Place Cancer Support Centre
33. Hereditary Breast & Ovarian Cancer Society of Alberta
34. Hereditary Breast & Ovarian Cancer Society of Montreal
35. Hope Spring Cancer Support Centre
36. Knot a Breast
37. Mastectomy Wear for Fighters and Survivors
38. Melanoma Network of Canada
39. Nanny Angel Network
40. Ovarian Cancer Canada
41. Peterborough’s Breast Cancer Survivor Team
42. Princess Margaret Hospital
43. Rethink Breast Cancer
44. Sarcoma Cancer Foundation of Canada
45. Sunnybrook Odette Cancer Centre
46. Survive and Thrive Expedition
47. Surviving Beautifully
48. Think Pink Direct
49. Thrive: Physical Activity for Cancer Survivors
50. Thunder Bay Breast Cancer Support Group
51. Willow Breast Cancer Support Canada
52. Women’s College Hospital
53. Young Adult Cancer Canada
Appendix J

Samples of Recruitment Notices Posted by Cancer Agencies

(Print screen)
Appendix J (Continue)

Samples of Recruitment Notices Posted by Cancer Agencies

Remember this fertility study?

A few weeks ago we put a call out for Samantha Yee who was recruiting five female survivors for her fertility research. A list of you have helped her out already, and now she’s on to the next phase of her project. She asked to share this message with you:

**Seeking Canadian female cancer survivors to participate in a web-based anonymous survey on Cancer, Fertility and Motherhood**

Fertility is an under-researched area in cancer care, and there are limited data on how the oncology system deals with the fertility concerns of young adults with cancer. The Faculty of Social Work at the University of Toronto is seeking female cancer survivors to participate in an online anonymous survey study on “cancer, fertility, and motherhood.” The survey will take approximately 30 to 45 minutes to complete.

**Eligibility requirements:**
1. female cancer survivor;
2. received a cancer diagnosis after 2000;
3. between the age of 19 and 30 when diagnosed with cancer;
4. received cancer treatment in Canada; and,
5. have completed cancer treatment.
Appendix J (Continue)
Samples of Recruitment Notices Posted by Cancer Agencies
(Print screen)
Appendix J (Continue)
Samples of Recruitment Notices Posted by Cancer Agencies
(Print screen)

Cancer, fertility and motherhood

Every year, approximately 85,000 Canadian women are diagnosed with cancer; of these, over 4,000 women are between the reproductive age range of 20 and 39. Fertility and motherhood are important quality of life issues for many young women with a history of cancer. However, very limited data are available to document how fertility matters are addressed when young women receive cancer care in Canada.

The University of Toronto Faculty of Social Work is seeking female cancer survivors to participate in an anonymous e-survey for a doctoral research project. The survey will take approximately 30 minutes to complete.

Eligibility

1) Female cancer survivor; 2) received a cancer diagnosis after 2000; 3) between the age of 18 and 39 when diagnosed with cancer; 4) received cancer treatment in Canada; and 5) have completed cancer treatment.

Visit the project website at http://cancerandfertility.com/ or access the e-survey at http://fluidsurveys.com/s/fertility. Survey respondents can participate in a draw to win an Amazon gift card.

Cancer, fertility and motherhood study

Fertility is an under-researched area in cancer care, and there are limited data on the views of Canadian cancer survivors on fertility and motherhood. Samantha Yue, a PhD candidate at the University of Toronto Faculty of Social Work, is seeking female cancer survivors to participate in an anonymous online survey on "cancer, fertility and motherhood". Eligible participants are:

1) female cancer survivor;
2) received a cancer diagnosis after 2000;
3) between the age of 18 and 39 when diagnosed with cancer;
4) received cancer treatment in Canada; and
5) have completed cancer treatment.

Visit the project website www.cancerandfertility.com for more information. Survey respondents can participate in a monthly draw to win a $50 Amazon gift certificate.
Appendix J (Continue)
Samples of Recruitment Notices Posted by Cancer Agencies
(Print screen)
Appendix J (Continue)

Samples of Recruitment Notices Posted by Cancer Agencies

(Print screen)

Thunder Bay Breast Cancer Support Group

Issue 742
October 2012

Contact us
Breast Cancer Support Group
3030 Avenue Place
Thunder Bay, ON P7B 4J2
418-686-1925 (voice)
bcso@tbymail.net
http://www.breastcancersupportgroup.com

Do you need someone to talk to? We would love to hear from you.
Call for support: Danielle Stuart 564-3641
Pamela Francis 248-9102
Heather Cole 592-7729
Dana Pegg 567-5601

Next Support Group Meeting:
October 10
7:00 p.m.
St. Michael and All Angel's Church
Read River Road

Less Stress Helps Breast Cancer Patients

By Sue Wingert
ON Mosaic Producer

It’s enough for a woman to go through one diagnosis of breast cancer, but when the cancer recurs it can be disheartening. Not only does the stress of reemerging breast cancer concern her, but also the potential of losing her quality of life, can also take a toll on her health.

So how can the medical community help these patients? According to a study in the publication Clinical Cancer Research, a Journal of the American Association for Cancer Research, stress reducing psychological interventions were found to help increase the quality of life and the survival rate among women with recurrent breast cancer and the long term.

A similar study called the Stress and Immunity Breast Cancer Project, also showed that after an average of 11 years of follow-up, women who received psychological intervention had a 49 percent reduction in breast cancer recurrence. In this study, 200 women were randomly assigned to receive either supportive counseling or stress management techniques. Participants in the current study included 200 women with newly diagnosed Stage I or II breast cancer. The women were randomized to receive psychological intervention or supportive counseling. Women in the psychological intervention group received stress management techniques designed to reduce anxiety and improve quality of life. Women in the control group were assigned to supportive counseling.

During follow-up, 42 percent of the women in the treatment group reported a decrease in their stress level. Women in the control group reported no change in their stress level.

In this newsletter...

Pumpkin Cream Cheese Muffins
Confections for Young Women
Afflicted by Breast Cancer
Cancer, Fertility and Motherhood Research Project
Luncheon of Hope

ZUMBA

ZUMBA fitness

Thunder Bay Breast Cancer Support Group

Issue 742
October 2012

Odds and Ends

2012 Luncheon of Hope with Libby Zinsmeier

Libby Zinsmeier is a prominent Canadian columnist covering health, the arts, and lifestyle issues. After working in television broadcasting covering treatment and politics for ten decades, she joined MD Media in 2004. She serves as Vice-President of News and Information for both Cancer Care Ontario and AMT. She is also publishing and hosting The Zumba Report, a special feature on all topics of interests to the baby boom generation. It covers everything from health and wealth, to style and culture. That’s the special sauce that’s going into the luncheon this year! Libby also writes a regular column for Zumba Magazine.

She has contributed to numerous publications including Forward Ontario, Metro Magazine, the Globe and Mail, and the National Post, where she writes a popular column on breast cancer called The Libya and Me blog. Cured Cancer – Living Well Is The Best Revenge – was published by Key Porter Books in October 2007.

Libby has been a print journalist with The Associated Press in Tbilisi, Georgia.
Appendix K
Samples of Recruitment Flyers in Paper Format

A web-based survey research study on
Cancer, Fertility and Motherhood

About the study
This is a doctoral research study entitled, “Cancer, fertility and motherhood: Addressing the fertility needs of young women with cancer in times of stress, uncertainty, and time pressure”. The study aims to examine how the fertility concerns of young female cancer patients were addressed in cancer care, and their perspectives of receiving fertility preservation services prior to commencing cancer treatment.

Eligibility criteria
1) Female cancer survivor, 2) received a cancer diagnosis after the year 2000, 3) between the ages of 18 and 39 at the time of cancer diagnosis, 4) received cancer treatment in Canada, and 5) have completed cancer treatment.

How to begin the web-based survey
Visit the project website www.cancerandfertility.com for more information or access the e-survey directly at http://fluidsurveys.com/s/fertility.

The survey will take approximately 30 to 45 minutes to complete. Survey respondents can participate in a draw to win an Amazon gift certificate.
Appendix K (Continue)
Samples of Recruitment Flyers in Paper Format

An anonymous web-based research study on Cancer, Fertility and Motherhood

Visit the project website at www.cancerandfertility.com or access the e-survey at http://fluidsurveys.com/s/fertility

An anonymous e-survey on Cancer, Fertility and Motherhood

Visit the project website www.cancerandfertility.com for more information or access the e-survey directly at http://fluidsurveys.com/s/fertility

The survey will take approximately 30 minutes to complete. Survey respondents can participate in a draw to win an Amazon gift certificate.

A doctoral e-survey research study on Cancer, Fertility and Motherhood

Visit the project website at www.cancerandfertility.com

A chance to win an Amazon gift card