

FERTILITY PRESERVATION IN WOMEN DIAGNOSED WITH CANCER: A PROPOSAL  
FOR A NURSING COMPETENCY FRAMEWORK

By:

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### **Dedication**

I dedicate this to my parents. Dad and Emma, thank you for always loving and supporting me unconditionally and showing me that kindness and helping others are the most important things in life. I especially dedicate this to my mom, Barbara. Mom, without your help, I wouldn’t have been able to do this. Thank you from the bottom of my heart.

### Abstract

Individuals diagnosed with cancer are at risk of compromised fertility as a side effect of cancer treatments. As the survival rate of patients is improving due to advancements in cancer regimens, there is an increased focus on family-building into survivorship. Although assisted reproductive technologies have made the banking and cryopreservation of gametes and reproductive tissue feasible, fertility preservation (FP) remains under-implemented. Barriers to accessing FP care affect all age groups and genders, however, the literature suggests that FP for women of child-bearing age can be particularly complex due to the invasive and potentially time-intensive nature of FP for women. This document will focus on the available knowledge on barriers and facilitators to care including the current and future role of the FP nurse. This knowledge will inform the development of an FP Nursing Competency Framework to help support the advancement of nurses in clinical practice and the improvement of care in this sub-specialty.

*Keywords:* Fertility Preservation, Oncofertility, Cancer, Women, Reproductive Age, Child-bearing Age, Survivorship, Nursing, Competencies.

**Table of Contents**

Acknowledgments	2
Dedication	2
Abstract	3
Introduction	5
Chapter 1: Fertility Preservation	6
Background	6
Significance	9
Methodology	10
Chapter 2: Overview of Relevant Knowledge	11
Barriers and Facilitators to Care	12
The Role of the Fertility Preservation Nurse	16
Chapter 3: Envisioning the Future Role of the Fertility Preservation Nurse	19
Knowledge Relevant to Nursing	19
Developing Skills and Knowledge: A Nursing Competency Framework	20
Chapter 4: Implications and Recommendations	25
Nursing Leadership	25
Nursing Research	26
Conclusion	28
References	29
Appendix A Nursing Competency Framework	39
Appendix B Competencies	40
Appendix C Resources for the Fertility Preservation Nurse	42

### Fertility Preservation in Women Diagnosed with Cancer

Individuals newly diagnosed with cancer are often at risk of compromised fertility from the gonadotoxic side effects of cancer therapies (Oktay et al., 2018). Since patients are living longer due to advancements in cancer treatments, this has brought attention to the importance of addressing their reproductive rights into survivorship, and the impact that interrupted reproduction may have on their well-being and quality of life (Woodruff, 2017). Advancements in assisted reproductive technologies in the last three decades have made possible the collection and cryopreservation of unfertilized oocytes, fertilized embryos, sperm, and reproductive tissue for patients to utilize once they are ready and have been deemed safe to proceed with reproduction by their physician (The Practice Committee of the ASRM, 2019). Even with the available technology to bank gametes for future reproductive use, accessing fertility preservation (FP) care continues to be a challenge for patients (Panagiotopoulou, Ghuman, Sandher, Herbert, & Stewart, 2018). Thus, FP remains underutilized and rates of referral to fertility specialists remain low varying between 10 and 54% (Anazodo et al., 2019; Korkidakis, Lajkosz, Green, Strobino, & Velez, 2019). What makes timely access to care particularly significant is that the ideal time to perform FP is within a small window between the initial diagnosis of cancer and cancer treatment (The Practice Committee of the ASRM, 2019). As there have not been any human studies focusing on the quality of oocytes or embryos after a course of chemotherapy, there is an urgency to access and coordinate care within the recommended time frame (The Practice Committee of the ASRM, 2019).

As an FP coordinator working within a fertility centre, I recognized some of the challenges evidenced in the literature, particularly for women of child-bearing age. Men also reported difficulty accessing care, however, FP is generally more straightforward, less invasive,

less disruptive to their cancer treatment schedule, and less costly (Peddie et al., 2012). In contrast, the pediatric population face their own unique complexities with FP, thus I have chosen to focus on the challenges for women of child-bearing age. With my experience working with this population, I knew there were opportunities to expand nursing's role to their full scope of practice in FP and I felt compelled to dedicate the last scholarly project of my degree program to advancing nursing's unique contribution to improving care for this underserved population.

The intention of this scholarly practice advancement research project (SPAR) is to articulate the nature of nursing competencies in the developing stages of knowledge and skill progression for a nurse in FP practice. Therefore, in this SPAR document, I will provide a background review on FP and an overview of relevant knowledge on barriers and facilitators to FP care. I will then explore the available knowledge about the current and future potentialities of the FP nurse role. Drawing from my clinical experience in this sub-specialty, I will provide an interpretation of this knowledge through a nursing lens by developing a competency framework that may serve as a guide for FP nurses to provide intentional and conscious nursing care and to prepare nurses to meet some of the gaps in care that are currently evidenced in the literature. Last, I will explore implications for future nursing leadership and research opportunities in this area.

## **Chapter 1: Fertility Preservation**

### **Background**

In 1971, the Department of Obstetrics and Gynaecology from the University of Edinburgh published an article describing the potential adverse effects of radiotherapy on the mammalian ovary leading to potential biochemical changes in the oocyte and temporary or permanent sterility (Baker, 1971). Further research identified that pelvic, brain, and full-body

irradiation and alkylating chemotherapy agents could impair reproductive health and ovarian function based on the agents used, the dose prescribed, and the age of the patient at the time of treatment (Sonmezer & Oktay, 2004). Common chemotherapeutic agents such as cyclophosphamide, cisplatin, and methotrexate were identified from a high to a low degree of gonadotoxicity, further assisting clinicians to identify patients at risk (Sonmezer & Oktay, 2004). However, it wasn't until the early 2000s that long term outcomes of cancer survivors began to be acknowledged, including the need to consider their reproductive future (Lee et al., 2006). In response to this growing awareness, international organizations such as the American Society for Clinical Oncology (ASCO), the National Institute for Health and Care Excellence (NICE), the Canadian Fertility and Andrology Society (CFAS), and the American Society for Reproductive Medicine (ASRM) developed guidelines recommending early discussion of potential infertility as a part of informed cancer treatment consent and prompt referral to fertility specialists for those interested or uncertain (Lee et al., 2006; NICE, 2014; Roberts, Tallon, & Holzer, 2014; The Practice Committee of the ASRM, 2013).

Concurrent with the advancements in cancer treatments, advancements in assisted reproductive technologies made possible the first live birth from a re-implanted embryo in 1978 (Steptoe & Edwards, 1978). Decades later, the controlled stimulation of ovaries for the banking and cryopreservation of fertilized embryos became standard practice (Lee et al., 2006). It was not until 2013 that the cryopreservation of the more fragile oocyte was made possible and was declared non-experimental (The Practice Committee of the ASRM, 2013). This was an important development, as it broadened possibilities for women who were either unpartnered or in a temporary relationship, did not wish to use donor sperm, or had ethical or religious objections to

creating embryos; it gave them the option to bank oocytes for later use (Levine, Kelvin, Quinn, & Gracia, 2015).

Other methods of FP include ovarian tissue cryopreservation, which is appropriate for women who are unable to delay cancer treatment to undergo a controlled ovarian stimulation cycle, and the only possibility for pre-pubertal females. Although ASRM in 2019 deemed ovarian tissue cryopreservation a non-experimental FP procedure, oocyte and embryo cryopreservation remain the principal methods of FP for women. There is a theoretical risk of reintroducing malignant cells with ovarian tissue transplantation and this technically challenging procedure is only feasible when there are available laboratory and surgical expertise (The Practice Committee of the ASRM, 2019). Another FP method is the use of gonadotropin-releasing hormone agonists (GnRHa). They act to temporarily protect the ovaries from premature ovarian insufficiency by suppressing ovarian function during chemotherapy. There are conflicting data on the efficacy of GnRHa, although there have been some positive data for their use with premenopausal breast cancer patients (Lambertini, Horicks, Del, Partridge, & Demeestere, 2019). Thus, GnRHa may be considered in instances where young women with breast cancer are not able to access FP services, but should not be recommended in lieu of established FP methods (Oktay et al., 2018; The Practice Committee of the ASRM, 2019).

In addition to advancements in assisted reproductive technologies, clinicians introduced an oral aromatase inhibitor during ovarian stimulation to decrease the effects of rising estradiol levels from maturing oocytes during the ovarian stimulation process, thus potentially minimizing the harmful effects of elevated estradiol levels on estrogen receptive breast and gynecological malignancies (Oktay et al., 2018). In a study of 337 breast cancer patients, researchers concluded that ovarian stimulation with letrozole supplementation likely would not increase the recurrence



risk of breast cancer in the first five years after diagnosis (Kim, Turan, & Oktay, 2016).

Furthermore, advances in Preimplantation Genetic Testing may address concerns regarding some heritable cancers, such as BRCA 1 and 2 mutations in offspring, by screening embryos so that only those embryos unaffected by the specific cancer gene would be transferred into a woman's, or her surrogate's, uterus (Ethics Committee of the ASRM, 2018).

The procedure of invitro-fertilization to collect oocytes and embryos is not remarkably different for FP purposes – a complete cycle typically takes 12-14 days and is normally timed with the start of menses (Letourneau et al., 2017). However, due to the urgency to start chemotherapy and radiation, the introduction of gonadotropin-releasing hormone antagonists has allowed for ovarian stimulation at any point in the menstrual cycle, providing the flexibility required to accommodate an oocyte or embryo collection in the time frame between diagnosis of cancer and the start of cancer treatment (Oktay et al., 2018). Therefore, an early discussion about infertility and a referral to a fertility specialist, along with effective decision-making support are key, particularly when the cancer diagnosis, prognosis, and treatment plan allow.

### **Significance**

In Canada, approximately 107,000 new cases of cancer were diagnosed in females in 2019, the most common to be breast cancer, and approximately 5,500 cases were in women between the ages of 20-39 years of age (Canadian Cancer Society, 2019). The risk of permanent infertility in women diagnosed with breast cancer below the age of 35 is approximately 10-20% and the risk increases tenfold for women in their late thirties (Canada & Schover, 2012).

Treatment plans may also include adjuvant hormone therapy, such as Tamoxifen, for the treatment of hormone-receptive cancers after chemotherapy and radiation, and as such may add an additional ten years to the delay in pregnancy (Burstein et al., 2014). This impact may be

significant given that age-related infertility is well-documented as a significant factor in the depletion of ovarian reserve (ASRM Committee, 2014). Moreover, a study on the long term outcomes of 497 women diagnosed with cancer found that there were no increases in the mortality or cancer recurrence rates in women who had elected to proceed with FP and that there were no significant delays in initiating cancer treatments when FP was elected, suggesting that electing FP may be considered a safe and reasonable option if the diagnosis and treatment plan permit (Letourneau et al., 2017; Moravek et al., 2018).

Further to the impact of potential infertility on women's physiological risk is its impact on women's psychological well-being. The inability to access FP care and information promptly can have long-term psychological effects on women as these barriers hinder their ability to make informed decisions about their care (Canada & Schover, 2012; Letourneau et al., 2012). Women have reported that cancer-related infertility caused emotional distress, regret, and resentment even 10 years into survivorship (Canada & Schover, 2012; Woodruff, 2017). Likewise, a study of 2,532 patients suggested that even if women chose not to pursue FP, they had less regret about their decision if they were given the initial information to make an informed decision (Letourneau et al., 2012). Thus, there are compelling reasons to explore solutions to these medical and quality of life issues related to cancer and infertility.

## **Methodology**

A narrative review is a critically interpretive and scholarly summary of a topic (Greenhalgh, Thorne, & Malterud, 2018). The focus of this approach is to broadly explore a subject matter in order to "extend our understanding of how and why a body of knowledge has evolved in the manner it has, and what sense we ought to make of it in our current challenges" (Thorne, 2018, p.2). For this reason, I chose to utilize this approach to understand the current

knowledge landscape of FP and women diagnosed with cancer and the extent to which the knowledge has been explored through a nursing lens. In addition, I concluded the subject of women diagnosed with cancer faced with a potential secondary diagnosis of infertility was not fit to be researched within a narrow guideline, but rather needed to be examined broadly to include what is known about the experiences of these women in this uniquely complex health phenomena in hopes to uncover depth and nuances that may influence our understanding (Thorne, 2019).

I have included in my literature search data from key quantitative and qualitative research articles, meta-syntheses, systematic reviews, international clinical practice guidelines, and grey literature, such as information from conference proceedings, with no limitations on time period. A limitation was set on English language literature only. I have utilized theoretical perspectives and frameworks to help guide my synthesis of the data, including the Ottawa Decision Support Framework (O'Connor, 2006), the Canadian Nurses Association (CNA) Code of Ethics for Registered Nurses (CNA, 2017), and the Oncofertility Model of Care (Anazodo, 2018). By drawing from my nursing clinical experience in this sub-specialty and a broad literature review on this topic, I aim to shape the understanding of this topic by interpreting findings through a nursing lens in order to present possibilities of what nursing's contribution to advancing care in this area may be.

## **Chapter 2: Overview of Relevant Knowledge**

FP is considered a fairly “young” specialty compared with well-established disciplines such as obstetrics and gynaecology or general surgery. It was Dr. Teresa Woodruff in 2006, an internationally renowned expert in ovarian biology, who coined the term “oncofertility” to describe this new and intersecting specialty of oncology and fertility (Oncofertility Consortium,

2015). I attribute this “newness” to be one of the reasons that the predominant focus in the literature has been on the challenges of establishing routine access to care, and for those able to gain access, establishing ways to support informed decision making. Many studies have highlighted the relevance of these practice gaps on this population by describing the experiences of patients within the context of a cancer diagnosis and infertility, and the implications that barriers to care may have on their psychological well-being and quality of life into survivorship. Equally, there have been evidence-based strategies suggested to support the FP patient, however translating these strategies to practice continues to present significant challenges (Anazodo, 2018; Anazodo et al., 2019; Panagiotopoulou et al., 2018).

### **Barriers and Facilitators to Care**

#### **Barriers**

The barriers to FP care can be described as anything that impedes access to care or hinders a patient’s ability to make an informed and value-based decision. Studies have suggested that barriers may be categorized into four obstacles: lack of adequate knowledge provision, lack of adequate emotional and psychological support, lack of referrals, and financial cost. (Panagiotopoulou et al., 2018; Parton, Ussher, & Perz, 2019; Peddie et al., 2012).

#### ***Lack of Adequate Knowledge Provision***

To access care or participate in decision-making about options, a patient must first be able to access the evidence-based knowledge required to be an active participant. The reasons for the lack of adequate knowledge provision are multi-faceted and complex. Some studies have suggested that this barrier may stem from the level of health care professional (HCP) training on FP and the resultant comfort level of clinicians to discuss options with patients (Quinn et al., 2009). Another reason cited was the assumptions and values that HCPs held regarding a number

of factors including a patient's diagnosis, emotional state, relationship status, age, gender, parity and socioeconomic status, which could impact on the quality of information provided (Parton et al., 2019; Peddie et al., 2012; Snyder & Tate, 2013; Wilkes, Coulson, Crosland, Rubin, & Stewart, 2010). For example, some studies suggested that men may be provided with more information on FP as sperm banking was considered more straightforward and less complex to organize, and women who were single or had previous children were assumed to have a lesser priority to proceed with FP by their HCPs (Parton et al., 2019; Peddie et al., 2012).

The American Society for Clinical Oncology (ASCO) updated their recommendations in 2013 on FP and cancer to expand the responsibility of educating and counseling beyond physicians to include other HCPs such as social workers and nurses; however, despite these suggestions, there remains confusion as to which group of professionals would be routinely assigned these responsibilities (Barbour, Porter, Peddie, & Bhattacharya, 2013; Loren et al., 2013). Similarly, one study suggested that 40% of the time oncologist expected the patient to initiate the conversation on FP, while other studies suggested that patients and oncology nurses preferred the oncologist to initiate FP discussions (Anazodo et al., 2019; Gorman, Usita, Madlensky, & Pierce, 2011; Murray, Chrisler, & Robbins, 2015; Wilkes et al., 2010). Thus, consideration of streamlining these expectations and processes should be a priority.

Lack of knowledge provision also impacts on the patient's decision-making process. For example, according to Ottawa's Decision Support Framework, decision quality is based on a patient's perceptions of being informed and whether their values have been considered (O'Connor, 2006). Therefore, inadequate information may significantly impact a patient's ability to make a high-quality health decision. Lack of evidence-based information may also impact a person's emotional state. For example, having misconceptions and fears about FP procedures,

such as what it may entail physiologically, lack of information on heritable cancers on offspring, or the statistics on the impact of FP on their survival and cancer recurrence, may create emotional distress that could impact on their decision-making ability (Flink, Kondapalli, & Kellar-Guenther, 2017; Parton et al., 2019; Snyder & Tate, 2013; Speller et al., 2019).

### ***Lack of Emotional and Psychological Support***

The impact of unmet emotional and psychological support may include a patient's inability to cope, problem-solve and a reduced capacity to make decisions (Stacey et al., 2013). This is significant, particularly in this context where a patient's capacity to make decisions on their care may already be compromised by the time-pressured nature of coordinating FP prior to cancer treatment, and the burden of having a dual diagnosis of cancer and potential infertility. For example, a study noted that patients perceived a reduced capacity to make a decision on FP due to feelings of being overwhelmed and distressed with the physical and emotional effects of cancer (Parton et al., 2019). Moreover, some studies have suggested that lack of knowledge and emotional support were also connected with higher levels of depression and distress related to cancer and fertility-related concerns (Logan, Perz, Ussher, Peate, & Anazodo, 2018). While many of the studies have focused on the impacts of emotional and psychological well-being of FP patients, some other studies have suggested that support should not only be available at the time of diagnosis but also into the survivorship period (Hill et al., 2012; Logan et al., 2018).

### ***Lack of Referrals***

The ASCO's clinical guidelines outlined that early discussion and referral to a fertility specialist is recommended to interested patients or to those that are uncertain or ambivalent (Oktay et al., 2018). However, referrals to fertility specialists and access to FP care remain low (Anazodo et al., 2019). For example, a study on patterns of referral for young women newly

diagnosed with cancer in Ontario found that referrals were low at 10.7%, even though the reported 5-year survival rate for breast cancer was 88% (Canadian Cancer Society, 2019; Korkidakis et al., 2019). Some studies have suggested that the lack of referrals may be attributed to a number of factors such as HCP's assumptions that a referral to a fertility specialist may not be the patient's priority, a lack of an established referral pathway and the lack of collaboration and communication between the oncology and fertility networks (Anazodo et al., 2019). Establishing a clear and routine referral pathway for eligible patients would be significant in improving patients' access to FP care; therefore addressing these barriers is viewed as a priority (Panagiotopoulou et al., 2018).

### ***Financial Cost of FP***

An invitro-fertilization cycle to collect oocytes or fertilized embryos can cost between \$5000-8000 CAD per cycle, and the yearly storage fee of the gametes may cost approximately \$100 -\$200 per month (Hendershot et al., 2016). In Canada, infertility due to cancer treatments is not covered by publicly funded healthcare, therefore access is limited to those with the financial means or those able to access charitable organizations that may be able to provide some financial relief (Ronn & Holzer, 2013). The cost of future use of banked oocytes and embryos was also cited as a financial concern for patients in their survivorship (Flink et al., 2017). A study at a Toronto fertility clinic noted that cost was cited as a barrier and a consideration for patients in their decision-making process; however, it did not specifically prevent patients in their study from accessing care (Hill et al., 2012). On the other hand, in another Canadian study, young women with breast cancer who wanted more children prior to their diagnosis and were offered FP stated that their main reason to decline was due to cost (Warner et al., 2019). Clearly, the impact of a patient's social determinants of health such as their socio-economic status must be

considered when caring for this vulnerable group including how nurses could advocate for financial support.

### **Facilitators**

Studies have also described facilitators to FP care that would help support overcoming barriers. Many of the facilitators are included in the criteria used to measure international models of care (MOC) in oncofertility. There are eight established oncofertility MOCs, five of which include the care of women of child-bearing age (Anazodo et al., 2019). Most are based in the United States with one MOC in Canada at McMaster University. Seven criteria have been established against which these established MOCs can be measured: patient educational material, healthcare professional education, an established referral process, a patient navigator, established collaborative partnerships, electronic notification for eligible patients, and psychological counseling (Anazodo et al., 2019). A systematic scoping review on current international practice and models of care further delineated successful components of an oncofertility MOC. They included: communication skill, oncofertility training for HCPs, reproductive survivorship care, fertility-related psychosocial support, ethical practice for oncofertility care, oncofertility medical care during FP, documentation, use of oncofertility patient decision aids (PtDAs), and referral pathways (Anazodo et al., 2019). This guidance provides a strong base to envision what may be required to facilitate access to care and decision-making; however, a more in-depth articulation of how these services might be enacted in a clinical setting would be useful.

### **The Role of the FP Nurse**

In order to envision the role nurses play to help address current practice gaps, it is important to examine the current definition of the FP role. The role of the FP nurse has been described in countries such as the United States and the United Kingdom; however, this role has



not been explicitly defined in the Canadian context. Currently, the Canadian Andrology and Fertility Society is developing competencies for the fertility nurse (CFAS, 2019).

### **Canada**

I fell into the role of an FP Coordinator based on my interest in the area of FP and my years of experience as a fertility nurse. Being an emerging specialty, the role was not clearly defined, however, it became apparent that the role must include the capacity to coordinate care with the oncology team, a basic understanding of cancer treatments and their impact on ovarian and uterine function, understanding available options for FP and its timing with cancer treatments, skill in discussing treatment costs, and most importantly, time and skillful support in decision-making for women in this very complex and time-pressured health crisis. The fertility specialist and I would coordinate care either directly with the oncologists or with the nurse manager of the oncology unit. Alternatively, in a large tertiary cancer care centre in Canada, advanced practice nurses provided education and resources for staff, coordinated care, and provided FP consultations (Hendershot et al., 2016). The provision of education to HCPs has been noted as a significant facilitator to the access of care and to aiding the decision-making process. Hence, including HCP education and training in the role of the FP nurse would be an important consideration.

### **International**

In the United States, the Oncofertility Consortium, an interdisciplinary organization based in Chicago that supports collaborative interdisciplinary scholarship and research on the reproductive future of cancer survivors, defined the FP nurse in the cancer-care context as the oncology nurse responsible for providing FP information and referral to a fertility specialist (The Oncofertility Consortium, 2019). This organization also described the FP patient navigator role

as a medical professional who provides female and male cancer patients with FP information and helps coordinate care (The Oncofertility Consortium, 2011). In some cases, patient navigators have been nurses. For example, an established FP program found that having an experienced nurse as a patient navigator facilitated referrals, provided the initial FP information to the patient, and improved the communication between the referring specialty, fertility, and the patient so that once FP was completed, the oncologist would be informed immediately to coordinate cancer treatment (Kennedy et al., 2018). I agree that having a designated patient navigator role would be critical in an FP program, however, I posit that preparing nursing staff working within oncology and fertility contexts to have the capacity to provide this type of coordinated care alongside the patient navigator may help to improve the quality and the delivery of care.

In the United Kingdom, the Royal College of Nursing provided a Clinical Professional Resource on Fertility Preservation in 2017. It described the role of the FP nurse as providing care to patients who have been diagnosed with a life-limiting disease that may affect their reproductive future and patients who have chosen FP for non-medical reasons such as delayed child-bearing due to life circumstances or those considering gender-reassignment surgery (Royal College of Nursing, 2017). The role of the FP nurse in this framework has been defined as comprising of two streams: one in a non-fertility specialty which included nurses in oncology, gynaecology, and hematology, and another for nurses in a specialized fertility setting. In this clinical professional resource, it was proposed that non-fertility specialists be responsible for the initial information provision of FP and establishing clear referral pathways to a fertility specialist. In the fertility specialist setting, it recommended that the fertility nurse ensured clear referral pathways, liaised with the non-fertility specialties, and provided flexibility in appointments so that patients could be seen quickly. A shared responsibility was to provide

appropriate counseling (Royal College of Nursing, 2017). I found this framework, which included both the non-fertility and fertility setting, to be helpful in distinguishing the potential roles that each specialty could hold in FP.

### **Chapter 3: Envisioning the Future Role of the FP Nurse**

To envision the future role of the FP nurse, it is important to examine the available literature on the barriers and facilitators to care and the current role of the FP nurse. By examining the literature, we can begin to determine the knowledge most relevant to nursing. Although there is no agreed-upon definition of nursing epistemology, it can be argued that the knowledge that is most relevant to nursing and best serves our disciplinary interests is generally concerned with knowledge and patterns of knowing that inform action and can be applied to clinical use. It is knowledge that is holistically positioned to understand the patterns of human experience without excluding the complexities and diversities of the individual (Thorne, Stephens, & Truant, 2016). By synthesizing the available knowledge through this disciplinary lens, I hope to provide suggestions for nursing's future role in addressing the key barriers to facilitate access to care and decision-making support. Moreover, I will provide suggestions on the knowledge, skills, and training required for nursing to meet these challenges.

#### **Knowledge Relevant to Nursing**

Nursing theorists such as Peplau, Henderson, and Watson described the nurse-patient relationship as therapeutic, where nurses instill trust and caring to patients in such a way that patients feel a sense of accomplishment (Raymond-Seniuk, Clune, & Gregory, 2015). It is this core belief in the therapeutic nurse-patient relationship that most attunes nurses to meeting patients' FP needs by communicating intentionally and meaningfully (CNA, 2017). I agree that other allied HCPs may be able to meet some of these practice gaps; after all, nursing does not

work in a silo. However, I propose that nursing is particularly well-positioned to meet some of these challenges in clinical practice based on our disciplinary value of relational connection and our proximity to the patient at the bedside. Therefore, focusing on the patterns of barriers, facilitating strategies, and the experiential outcomes of patients in the literature may provide direction on how nursing could develop their role to their full scope of practice.

### **Developing Skills and Knowledge: A Nursing Competency Framework**

I propose that the skills and knowledge of the FP nurse can be divided into three levels: the generalist nurse in oncology and fertility, the specialized FP nurse in oncology and fertility, and the expert/specialist nurse in FP (see Appendix A). These levels of expertise have been adapted from the Canadian Association of Nurses in Oncology (The Canadian Association of Nurses in Oncology, 2015). I will utilize this framework to articulate the progression of skills, knowledge, and training of the FP nurse to convey the methods through which nursing may be able to meet the evident practice gaps in FP. It is important to distinguish that the skills and knowledge needs will be different depending on the specialty that the nurse works within. For example, an oncology nurse may require more knowledge of basic fertility and reproduction to support the FP patient and, conversely, the fertility nurse may require more knowledge of the types of cancer treatment regimes.

The literature has suggested that barriers to care can be divided into four obstacles: lack of information provision, lack of emotional and psychological support, lack of referral pathways, and the financial cost of FP. To analyze their relevance to nursing, I have divided the barriers into two categories which will encompass all four of these obstacles. Within these two constructs, the skills and knowledge required by nursing to meet some of these challenges will be described.

### **Access to Care**

Nursing's ethical foundation provides direction for nurses to advocate for fair treatment and distribution of resources, and equitable access to healthcare for all (Canadian Nurses Association, 2017). There are four skills in the clinical setting that may facilitate access to care: standardized provision of FP information, initiation of the referral process, forming interdisciplinary relationships to establish referral pathways, and advocacy and provision of resources for financial support. Each skill will be described with the nursing knowledge and level of expertise required.

At the generalist level, both the oncology and fertility nurses will require a background on basic knowledge of cancer treatments and basic reproduction. Nurses at this level will also require a basic level of knowledge on FP options. At the specialized level, more in-depth knowledge of FP such as the risks and benefits of each option would be expected. Nurses may be the first contact that FP patients have with the clinic, therefore providing nurses with the skill and capacity to provide standardized FP information, whether it be in the form of a written resource or providing an online resource, would be important. Furthermore, providing routine FP information regardless of the patient's age, gender, parity, sexual orientation, cancer diagnosis, or socioeconomic status may help to mitigate the attitudes and assumptions of HCPs that might influence the amount and quality of information provided (Parton et al., 2019; Peddie et al., 2012). Providing standardized information will give patients the ability to discuss FP with their oncologist and fertility specialist, whether FP is appropriate for them or not.

At both the generalist and specialized level, nurses working in oncology may also routinely include a referral form in the patient's chart for the oncologist to complete. It is at the discretion of the oncologist to decide if a referral is appropriate; however, this will provide ease

to the process and a reminder to the HCP to include discussion on infertility as a part of the consenting process for cancer treatment. At the expert level, developing policies and procedures so that routine information provision and referrals are standardized would be important.

Moreover, as a Delphi study of experts in the Netherlands suggested, young female breast cancer patients should receive some FP information shortly after diagnosis (Garvelink et al., 2012); therefore, nursing can support the oncology team by providing the resources needed to prepare for the initial discussion and referral process. This would likely be the most useful for the oncology nurse working on an oncology unit.

Collaborative relationships may need to be initiated by the oncologists or fertility specialists; however, they can also be initiated by the more specialized FP nurse or expert. Once a contact person or group has been established, then a method of contact for sending an urgent referral should be agreed upon, with the patient expedited to be seen by a fertility specialist. Expediting the referral process for this population will allow more time for FP discussions with the fertility specialist, decision-making, and ultimately time to collect oocytes or embryos before the initiation of cancer treatment. The challenge, in some cases, is that not all fertility centres accept oncology referrals or have on-site invitro fertilization capabilities (Yee, Buckett, Campbell, Yanofsky, & Barr, 2012). Therefore, having a national database of fertility clinics or time to investigate participating fertility clinics would be useful.

Specialized training in communicating the cost of FP to patients may help nurses to feel knowledgeable and ready to discuss cost, especially when they are not used to discussing monetary payment for health services in a publicly funded healthcare system. By addressing nurses' discomfort in discussing certain topics such as cost, it may increase the likelihood that this topic is broached (Quinn et al., 2009). The generalist nurse may be able to provide the initial

cost information to the patient and provide access to application forms for non-profit organizations such as Fertile Future, which runs the Power of Hope cost reduction program for patients seeking FP procedures (Fertile Future, 2017). The specialized FP nurse may be able to provide more specific costs related to FP, including use of gametes post-cancer treatments into survivorship, and the process and cost of surrogacy if required. Similarly, documenting the cost discussion and the patient's ability or inability to pay would be recommended, as what is made visible in patient records renders it actionable (Pauly, MacKinnon, & Varcoe, 2009). At any level, adding nursing's collective voice to advocate for FP coverage for cancer-related infertility on a broader societal level would be in line with nursing's disciplinary mandate (CNA, 2017). FP nurses could participate in advocacy groups organized through professional nursing associations, nursing special interest groups in FP, or nursing staff on a unit.

### **Decision-Making Support**

Decision-making can be evaluated broadly from a patient-centred care perspective. Patient-centred care has been designated as one of the priorities of British Columbia's Ministry of Health initiatives and a core belief in nursing's Code of Ethics (British Columbia Ministry of Health, 2015; CNA, 2017). At the core of patient-centred care is the process of shared decision-making which involves patients and HCPs collaborating to reach an informed and value-sensitive healthcare decision (Makoul & Clayman, 2006). It is described as having three essential components: recognizing the need for a decision, understanding the best available evidence, and incorporating the patient's values and preferences (Légaré & Wittman, 2013). I will include a fourth component which is supporting a patient's emotional well-being. Although a certain level of negative emotion can propel a patient to act, emotional distress can often thwart problem-solving and coping skills; thus supporting patients emotionally is an important consideration to

their decision-making process (Stacey et al., 2013). As noted earlier, a decision that is informed and value-based improves the quality of the decision and decreases decisional regret (O'Connor, 2006). Therefore, the following skills and knowledge of FP decision-making will be described with these four essential components as a guide.

Providing the initial FP information helps patients recognize the need for a decision. As described previously, the generalist oncology nurse will likely be the first point of contact for the patient. Later, a more in-depth discussion of the different FP options, including evidence-based knowledge on benefits and risks of each option and support for clarification of patients' values on each option can be undertaken by the specialized FP nurse in either oncology or fertility. Skills associated with supportive communication would be necessary for this level of care and likely would be beyond the generalist nursing level. These skills could include knowledge and training on the use of PtDAs, which are evidenced-based tools to facilitate patients to make complex health decisions (Stacey et al., 2017). Some studies have also suggested that when PtDAs were used, the likelihood of referrals to a fertility specialist increased (Peate et al., 2012). Research has also suggested that an improvement in knowledge and clarity on what matters most to them regarding health options, may also increase patients' participation in their care (Stacey et al., 2017).

The literature has described patients experiencing patterns of distress, anxiety, fear, and feeling overwhelmed with the prospect of decision-making on FP (Parton et al., 2019; Snyder & Tate, 2013). From a practical perspective, nursing's proximity to the bedside and the nurse-patient therapeutic relationship could provide the climate for the patient's emotional state to be attended to. Nurses at all levels of expertise will require the skills and knowledge to distinguish whether more specialized psychosocial counseling is required. In addition, skill in including



family and significant others in the decision-making process may be useful. For example, in a study of 27 young women diagnosed with cancer, the authors noted that one of the main contributing factors to patients' decision-making on FP was the influence of their decision partners (Hershberger, Sipsma, Finnegan, & Hirshfeld-Cytron, 2016). Moreover, including family and significant others in the decision-making process adheres to the recognized principles of shared decision-making and may help the patient feel supported that the decision has been well made.

### **Implications and Recommendations**

#### **Nursing Leadership**

At the expert/specialist level, the nurse leader's role can be described in six areas of expertise: advocacy leadership, systems leadership, education and training, interdisciplinary collaboration, advanced clinical care planning, and research (Canadian Nurses Association, 2008). The nurse expert may lead the team by advocating for healthcare access to policymakers and government legislators. For example, this may be in the form of providing data to legislators regarding the inhibitory cost of FP on patients' access to care. Second, the nurse expert may support systems leadership to ensure FP policies and procedures are clear, including guidance for the referral process, developing a staffing model to allow for evidence-based support and adequate time for decision-making, and ensuring role clarity of FP team members.

Third, the nurse expert can ensure that training and evidence-based educational opportunities and professional development are available to staff. This includes finding evidence-based resources for HCPs and patients on the unit. It also includes arranging experts to provide in-services on specialized topics in FP such as ethical considerations. Fourth, the nurse expert can form collaborations between oncology, fertility, genetic counselors, and psychosocial

counselors so that referral pathways are established and routine. Fifth is nursing's expert capacity to coordinate advanced care planning for more complex FP cases. For example, included in the successful components of an oncofertility model are the medical considerations during FP. This may include more complicated cases where an anesthesia consult is required, special consideration is necessary due to the site of the tumour, or there is a need for blood product support during FP based on the patient's cancer diagnosis (Anazodo et al., 2019). Leading the coordination of care by connecting specialties in comprehensive care planning and communicating the plan to staff would be critical to patient safety and optimizing care. Last is ensuring that research to advance care in this population continues. Specifically, it would be important for nurse leaders to conduct research through a nursing lens so that nursing knowledge and perspectives are explored and benefits to nursing practice are prioritized. While many of these areas of expertise are described as competencies of the graduate prepared Advanced Practice Nurse (Canadian Nurses Association, 2008), exceptionally experienced nurses may attain this level of practice without the benefit of formal graduate education.

### **Nursing Research**

While much of FP research has focused on the perspectives of the FP patient in an oncology setting, less research has focused on their perspectives in a fertility setting. (Panagiotopoulou et al., 2018; Wright, Norton, & Geary, 2018). The FP nurse could conduct a qualitative research study to fill this knowledge gap as the evidence gained could help inform how nursing could better meet the needs of the FP patient in the fertility setting. For example, one study conducted at a fertility clinic in Toronto described the FP breast cancer patients' preference to have a different level of service from other infertility patients at the clinic (Hill et al., 2012). This result provided a strong starting point to expand on the FP patients' perspective

in the fertility setting and an opportunity for nursing to further explore patients' needs in order to improve care in this clinical practice setting.

Similarly, there is a paucity of research on the perspective of the FP nurse, particularly in the fertility setting (Keim-Malpass et al., 2018; Murray et al., 2015). By conducting research studies on the perspective of the FP nurse, this may extend our understanding of nursing's requirements to function at their full scope of practice in the fertility setting, and in turn, may inform FP programming. For example, a study by researchers from the Leicester School of Nursing in the UK, conducted an integrative phenomenological analysis of nurses' experiences of fertility-related discussions with teenagers and young adults at a teenage cancer unit (Wright et al., 2018). Researchers noted that nurses working in this oncology setting perceived having a lack of knowledge which resulted in their avoidance of fertility-related discussions. Findings suggested that including nursing FP education in programming would likely improve nurses' capacity to have fertility discussions with their patient population. Conducting a similar qualitative study focusing on FP nurses in the fertility setting and their perspectives on fertility-related decision-making discussions with patients may also help to explore those knowledge gaps and any potential solutions that could improve care for patients in the fertility setting.

Another research project that could be conducted by nurses would be examining the referral patterns of women of child-bearing age diagnosed with breast cancer in provinces across Canada. As described earlier, a study conducted by Korkidakis et al.(2019), found referral rates for women of child-bearing age newly diagnosed with cancer in Ontario were at 10.7% in 2016. The knowledge gained on how other provinces fair in their referral patterns may help to distinguish how provincial differences in the referral process may influence access to care for this population and could highlight areas of FP programming in need of improvement.

### **Conclusion**

While evidence-based components for a successful FP practice are available, guidelines have been less specific about how these successful components should be executed and by whom (Anazodo et al., 2019; Barbour et al., 2013). Nursing's disciplinary mandate of conscious and relational practice positions nurses strongly to coordinate and execute FP care within the interdisciplinary team. By developing a framework for FP nurses, I hope to articulate how these successful components can be practically applied in the clinical setting and provide guidance to FP nurses as they progress through their levels of expertise development. Ultimately, I hope the Nursing Competency Framework I have proposed will translate to improving care for this underserved population and may serve as a guide for nurse leaders in oncology and fertility who are interested in structuring an FP program in their clinical practice settings.

## References

- Anazodo, A. (2018). *Models of care: Providing fertility preservation for cancer patients*. Retrieved from [https://oncofertility.northwestern.edu/sites/oncofertility/files/Antoinette\\_Anazodo\\_2018\\_OCC\\_Slides\\_rfs.pdf](https://oncofertility.northwestern.edu/sites/oncofertility/files/Antoinette_Anazodo_2018_OCC_Slides_rfs.pdf)
- Anazodo, A., Laws, P., Logan, S., Saunders, C., Travaglia, J., Gerstl, B., ... Sullivan, E. (2019). How can we improve oncofertility care for patients? A systematic scoping review of current international practice and models of care. *Human Reproduction Update*, 25(2), 159–179. <https://doi.org/10.1093/humupd/dmy038>
- ASRM Committee. (2014). *Female age-related fertility decline: Committee Opinion. Fertility and Sterility* (Vol. 101). American Society for Reproductive Medicine. <https://doi.org/10.1016/j.fertnstert.2013.12.032>
- Baker, T. (1971). Radiosensitivity of mammalian oocytes with particular reference to the human female. *American Journal of Obstetrics and Gynecology*, 110, 746.
- Barbour, R., Porter, M. A., Peddie, V. L., & Bhattacharya, S. (2013). Counselling in the context of fertility and cancer: Some sociological insights. *Human Fertility*, 16(1), 54–58.
- British Columbia Ministry of Health. (2015). *The British Columbia Patient-Centred Care Framework*. Retrieved from [https://www.health.gov.bc.ca/library/publications/year/2015\\_a/pt-centred-care-framework.pdf](https://www.health.gov.bc.ca/library/publications/year/2015_a/pt-centred-care-framework.pdf)
- Burstein, H. J., Temin, S., Anderson, H., Buchholz, T. A., Davidson, N. E., Gelmon, K. E., ... Griggs, J. J. (2014). Adjuvant endocrine therapy for women with hormone receptor-positive breast cancer: American Society of Clinical Oncology clinical practice guideline focused update. *Journal of Clinical Oncology*, 32(21), 2255–2269.

<https://doi.org/10.1200/JCO.2013.54.2258>

Canada, A. L., & Schover, L. R. (2012). The psychosocial impact of interrupted childbearing in long-term female cancer survivors. *Psycho-Oncology*, *21*(2), 134–143.

<https://doi.org/10.1002/pon.1875>

Canadian Cancer Society. (2019). Survival statistics for breast cancer. Retrieved October 11, 2019, from <http://www.cancer.ca/en/cancer-information/cancer-type/breast/prognosis-and-survival/survival-statistics/?region=bc>

Canadian Fertility & Andrology Society. (2019). CFAS Nursing competencies: Working document. Retrieved November 7, 2019, from <https://cfas.ca/clinical-practice-guidelines.html>

Canadian Nurses Association. (2008). *Advanced nursing practice: A national framework*.

Canadian Nurses Association. (2017). *Code of Ethics*. Retrieved from <https://www.cna-aiic.ca/~media/cna/page-content/pdf-en/framework-for-the-practice-of-registered-nurses-in-canada.pdf?la=en>

Ethics Committee of the ASRM. (2018). Fertility preservation and reproduction in patients facing gonadotoxic therapies: An ethics committee opinion. *Fertility and Sterility*, *110*(3), 380–386. <https://doi.org/10.1016/j.fertnstert.2018.05.034>

Fertile Future. (2017). Power of hope cost reduction program. Retrieved from <https://fertilefuture.ca/programs/power-of-hope/>

Flink, D. M., Kondapalli, L. A., & Kellar-Guenther, Y. (2017). Priorities in Fertility Decisions for Reproductive-Aged Cancer Patients: Fertility Attitudes and Cancer Treatment Study.

*Journal of Adolescent & Young Adult Oncology*, *6*(3), 435–443.

<https://doi.org/10.1089/jayao.2016.0072>

- Garvelink, M. M., Kuile, M. M., Louwé, L. A., Carina, G. J. M., Stiggelbout, A. M., Garvelink, M. M., ... Carina, G. J. M. (2012). A delphi consensus study among patients and clinicians in the Netherlands on the procedure of informing young breast cancer patients about fertility preservation. *Acta Oncologica*, *51*(8), 1062–1069.  
<https://doi.org/10.3109/0284186X.2012.702927>
- Gorman, J. R., Usita, P. M., Madlensky, L., & Pierce, J. P. (2011). Young breast cancer survivors: Their perspectives on treatment decisions and fertility concerns. *Cancer Nursing*, *34*(1), 32–40. <https://doi.org/10.1097/NCC.0b013e3181e4528d>
- Greenhalgh, T., Thorne, S., & Malterud, K. (2018). Time to challenge the spurious hierarchy of systematic over narrative reviews? *European Journal of Clinical Investigation*, *48*(6), e12931. <https://doi.org/10.1111/eci.12931>
- Hendershot, E., Maloney, A.-M., Fawcett, S., Sarvanantham, S., McMahon, E., Gupta, A., & Mitchell, L. (2016). Advanced practice nurses: Improving access to fertility preservation for oncology patients. *Canadian Oncology Nursing Journal*, *26*(1), 40–45.  
<https://doi.org/10.5737/236880762614045>
- Hershberger, P. E., Sipsma, H., Finnegan, L., & Hirshfeld-Cytron, J. (2016). Reasons why young women accept or decline fertility preservation after cancer diagnosis. *JOGNN - Journal of Obstetric, Gynecologic, and Neonatal Nursing*, *45*(1), 123–134.  
<https://doi.org/10.1016/j.jogn.2015.10.003>
- Hill, K. A., Nadler, T., Mandel, R., Burlein-Hall, S., Librach, C., Glass, K., & Warner, E. (2012). Experience of young women diagnosed with breast cancer who undergo fertility preservation consultation. *Clinical Breast Cancer*, *12*(2), 127–132.  
<https://doi.org/10.1016/j.clbc.2012.01.002>

Keim-Malpass, J., Fitzhugh, H. S., Smith, L. P., Smith, R. P., Erickson, J., Douvas, M. G., ...

Duska, L. (2018). What is the role of the oncology nurse in fertility preservation counseling and education for young patients? *Journal of Cancer Education*, 33(6), 1301–1305.

<https://doi.org/10.1007/s13187-017-1247-y>

Kennedy, P., Ginsburg, E., Whitney, P., Srouji, S., Ashby, R., Gramolini, R., & Goldman, R.

(2018). A nurse navigator dramatically improves an established fertility preservation program. *Fertility & Sterility*, 110(4), e86.

Kim, J., Turan, V., & Oktay, K. (2016). Long-term safety of letrozole and gonadotropin

stimulation for fertility preservation in women with breast cancer. *Journal of Clinical*

*Endocrinology and Metabolism*, 101(4), 1364–1371. <https://doi.org/10.1210/jc.2015-3878>

Korkidakis, A., Lajkosz, K., Green, M., Strobino, D., & Velez, M. P. (2019). Patterns of referral

for fertility preservation among female adolescents and young adults with breast cancer: A population-based study. *Journal of Adolescent and Young Adult Oncology*, 8(2), 197–204.

<https://doi.org/10.1089/jayao.2018.0102>

Lambertini, M., Horicks, F., Del, L., Partridge, A. H., & Demeestere, I. (2019). Ovarian

protection with gonadotropin-releasing hormone agonists during chemotherapy in cancer patients : From biological evidence to clinical application. *Cancer Treatment Reviews*,

72(November 2018), 65–77. <https://doi.org/10.1016/j.ctrv.2018.11.006>

Lee, S. J., Schover, L. R., Partridge, A. H., Patrizio, P., Wallace, W. H., Hagerty, K., ... Oktay,

K. (2006). American society of clinical oncology recommendations on fertility preservation in cancer patients. *Journal of Clinical Oncology*, 24(18), 2917–2931.

<https://doi.org/10.1200/JCO.2006.06.5888>

Légaré, F., & Witteman, H. O. (2013). Shared decision making: Examining key elements and



barriers to adoption into routine clinical practice. *Health Affairs*, 32(2), 276–284.

<https://doi.org/10.1377/hlthaff.2012.1078>

Letourneau, J. M., Ebbel, E. E., Katz, P. P., Katz, A., Ai, W. Z., Chien, A. J., ... Rosen, M. P.

(2012). Pretreatment fertility counseling and fertility preservation improve quality of life in reproductive age women with cancer. *Cancer*, 118(6), 1710–1717.

<https://doi.org/10.1002/cncr.26459>

Letourneau, J. M., Sinha, N., Wald, K., Harris, E., Quinn, M., Imbar, T., ... Rosen, M. (2017).

Random start ovarian stimulation for fertility preservation appears unlikely to delay initiation of neoadjuvant chemotherapy for breast cancer. *Human Reproduction*, 32(10),

2123–2129. <https://doi.org/10.1093/humrep/dex276>

Levine, J. M., Kelvin, J. F., Quinn, G. P., & Gracia, C. R. (2015). Infertility in reproductive-age

female cancer survivors. *Cancer*, 121(10), 1532–1539. <https://doi.org/10.1002/cncr.29181>

Logan, S., Perz, J., Ussher, J. M., Peate, M., & Anazodo, A. (2018). A systematic review of patient oncofertility support needs in reproductive cancer patients aged 14 to 45 years of age.

*Psycho-Oncology*, 27(2), 401–409. <https://doi.org/10.1002/pon.4502>

Loren, A. W., Mangu, P. B., Beck, L. N., Brennan, L., Magdalinski, A. J., Partridge, A. H., ...

Oktay, K. (2013). Fertility preservation for patients with cancer: American Society of Clinical Oncology clinical practice guideline update. *Journal of Clinical Oncology*, 31(19), 2500–2510. <https://doi.org/10.1200/JCO.2013.49.2678>

Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making in medical encounters. *Patient Education and Counseling*, 60(3), 301–312.

<https://doi.org/10.1016/j.pec.2005.06.010>

Moravek, M. B., Confino, R., Smith, K. N., Kazer, R. R., Klock, S. C., Lawson, A. K., ...

- Pavone, M. E. (2018). Long-term outcomes in cancer patients who did or did not pursue fertility preservation. *Fertility & Sterility*, *109*(2), 349–355.  
<https://doi.org/10.1016/j.fertnstert.2017.10.029>
- Murray, A. N., Chrisler, J. C., & Robbins, M. L. (2015). Oncology nurses report attitudes and barriers to discussing fertility preservation. *Clinical Journal of Oncology Nursing*, *20*(4), 93–100.
- NICE. (2014). Cryopreservation to preserve fertility in people diagnosed with cancer. Retrieved from <https://pathways.nice.org.uk/pathways/fertility/cryopreservation-to-preserve-fertility-in-people-diagnosed-with-cancer#content=view-node%3Anodes-providing-information-about-cryopreservation>
- O'Connor, A. (2006). Ottawa decision support framework to address decisional conflict.  
Retrieved from [www.ohri.ca/decisionaid](http://www.ohri.ca/decisionaid)
- Oktaý, K., Harvey, B. E., Partridge, A. H., Quinn, G., Reinecke, J., Taylor, H., ... Loren, A. W. (2018). Fertility preservation in patients with cancer: ASCO clinical practice guideline update. *Journal of Clinical Oncology*, *36*(19), 1994–2001.  
<https://doi.org/10.1200/JCO.2018.78.1914>
- Oncofertility Consortium. (2015). About the oncofertility consortium. Retrieved from <https://oncofertility.northwestern.edu/about-oncofertility-consortium>
- Panagiotopoulou, N., Ghuman, N., Sandher, R., Herbert, M., & Stewart, J. A. (2018). Barriers and facilitators towards fertility preservation care for cancer patients: a meta-synthesis. *European Journal of Cancer Care*, *27*(1), 1. <https://doi.org/10.1111/ecc.12428>
- Parton, C., Ussher, J. M., & Perz, J. (2019). Hope , burden or risk : A discourse analytic study of the construction and experience of fertility preservation in the context of cancer. *Psychology*

& *Health*, 34(4), 456–477. <https://doi.org/10.1080/08870446.2018.1543764>

Pauly, B. M., MacKinnon, K., & Varcoe, C. (2009). Revisiting “who gets care?”: Health equity as an arena for nursing action. *Advances in Nursing Science*, 32(2), 118–127.

<https://doi.org/10.1097/ANS.0b013e3181a3afaf>

Peate, M., Meiser, B., Cheah, B. C., Saunders, C., Butow, P., Thewes, B., ... Friedlander, M. (2012). Making hard choices easier: A prospective, multicentre study to assess the efficacy of a fertility-related decision aid in young women with early-stage breast cancer. *British Journal of Cancer*, 106(6), 1053–1061. <https://doi.org/10.1038/bjc.2012.61>

Peddie, V. L., Porter, M. A., Barbour, R., Culligan, D., MacDonald, G., King, D., ...

Bhattacharya, S. (2012). Factors affecting decision making about fertility preservation after cancer diagnosis: A qualitative study. *BJOG: An International Journal of Obstetrics and Gynaecology*, 119(9), 1049–1057. <https://doi.org/10.1111/j.1471-0528.2012.03368.x>

Quinn, G. P., Vadaparampil, S. T., King, L., Miree, C. A., Wilson, C., Raj, O., ... Albrecht, T. L. (2009). Impact of physicians’ personal discomfort and patient prognosis on discussion of fertility preservation with young cancer patients. *Patient Education and Counseling*, 77(3), 338–343. <https://doi.org/10.1016/j.pec.2009.09.007>

Raymond-Seniuk, C., Clune, L., & Gregory, D. (2015). Nursing theory and theories used in nursing. In *Fundamentals: Perspectives on the art and science of Canadian nursing* (pp. 192–204). Philadelphia: Wolters Kluwer.

Roberts, J., Tallon, N., & Holzer, H. (2014). *Fertility preservation in reproductive age woman facing gonadotoxic treatments: CFAS Clinical practice guidelines*. Retrieved from

[https://cfas.ca/wp-content/uploads/2016/03/CFAS\\_CPG\\_Fertility\\_Preservation\\_2014.pdf](https://cfas.ca/wp-content/uploads/2016/03/CFAS_CPG_Fertility_Preservation_2014.pdf)

Ronn, R., & Holzer, H. E. G. (2013). Oncofertility in Canada: An overview of Canadian practice

and suggested action plan. *Current Oncology*, 20(5), 465–474.

<https://doi.org/10.3747/co.20.1361>

Royal College of Nursing. (2017). *Fertility preservation: Clinical professional resource*.

<https://doi.org/10.1002/9781444393958.ch17>

Snyder, K. A., & Tate, A. L. (2013). What to do now? How women with breast cancer make fertility preservation decisions. *Journal of Family Planning and Reproductive Health Care*, 39(3), 172–178. <https://doi.org/10.1136/jfprhc-2011-100286>

Sonmezer, M., & Oktay, K. (2004). Fertility preservation in female patients. *Human Reproduction Update*, 10(3), 251–266. <https://doi.org/10.1093/humupd/dmh021>

Speller, B., Sissons, A., Daly, C., Facey, M., Kennedy, E., Metcalfe, K., & Baxter, N. (2019). An evaluation of oncofertility decision support resources among breast cancer patients and health care providers. *BMC Health Services Research*, 19(1), 1–13. <https://doi.org/http://dx.doi.org/10.1186/s12913-019-3901-z>

Stacey, D., Kryworuchko, J., Belkora, J., Davison, B. J., Durand, M. A., Eden, K. B., ... Street Jr, R. L. (2013). Coaching and guidance with patient decision aids: A review of theoretical and empirical evidence. *BMC Medical Informatics and Decision Making*, 13(2), S11-6947-13-S2-S11. Epub 2013 Nov 29. <https://doi.org/10.1186/1472-6947-13-S2-S11> [doi]

Stacey, D., Légaré, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., ... Trevena, L. (2017). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*, (4). <https://doi.org/10.1002/14651858.CD001431.pub5>

Step toe, P., & Edwards, R. (1978). Birth after the reimplantation of a human embryo. *The Lancet*, 312(8085), 366.

The Canadian Association of Nurses in Oncology. (2015). Roles in oncology nursing. Retrieved

March 20, 2020, from <https://www.cano-acio.ca/page/OncologyNursingRoles>

The Oncofertility Consortium. (2011). Reproedia: A reproductive lexicon. Retrieved March 28, 2020, from <https://www.reproedia.org/patient-navigator>

The Oncofertility Consortium. (2019). The role of nurses in fertility preservation. Retrieved from <https://oncofertility.northwestern.edu/resources/nurses>

The Practice Committee of the ASRM. (2013). Fertility preservation in patients undergoing gonadotoxic therapy or gonadectomy: A committee opinion. *Fertility and Sterility*, *100*(5), 1214–1223. <https://doi.org/10.1016/j.fertnstert.2013.08.012>

The Practice Committee of the ASRM. (2019). Fertility preservation in patients undergoing gonadotoxic therapy or gonadectomy: A committee opinion. *Fertility and Sterility*, *112*(6), 1022–1033. <https://doi.org/10.1016/j.fertnstert.2019.09.013>

Thorne, S. (2018). Rediscovering the “Narrative” review. *Nursing Inquiry*, *25*(3), e12257. <https://doi.org/10.1111/nin.12257>

Thorne, S. (2019). On the Evolving World of What Constitutes Qualitative Synthesis. *Qualitative Health Research*, *29*(1), 3–6. <https://doi.org/10.1177/1049732318813903>

Thorne, S., Stephens, J., & Truant, T. (2016). Building qualitative study design using nursing’s disciplinary epistemology. *Journal of Advanced Nursing*, *72*(2), 451–460.

<https://doi.org/10.1111/jan.12822>

Warner, E., Yee, S., Seminsky, M., Lipson, D., Glass, K., Foong, S., ... Quan, M. (2019).

Barriers to fertility preservation in a prospective pan-Canadian study of young women with breast cancer. In *2019 ASCO Quality Care Symposium*.

[https://doi.org/10.1200/JCO.2019.37.27\\_suppl.136](https://doi.org/10.1200/JCO.2019.37.27_suppl.136)

Wilkes, S., Coulson, S., Crosland, A., Rubin, G., & Stewart, J. (2010). Experience of fertility

preservation among younger people diagnosed with cancer. *Human Fertility*, 13(3), 151–158.

Woodruff, T. K. (2017). Fertility lost-fertility found: Narratives from the leading edge of oncofertility. *Narrative Inquiry in Bioethics*, 7(2), 147–150.

<https://doi.org/10.1353/nib.2017.0044>

Wright, E., Norton, W., & Geary, M. (2018). Nurses' experiences of undertaking fertility-related discussions with teenagers and young adults with cancer: An interpretive phenomenological analysis, (January), 2860–2870. <https://doi.org/10.1111/jan.13804>

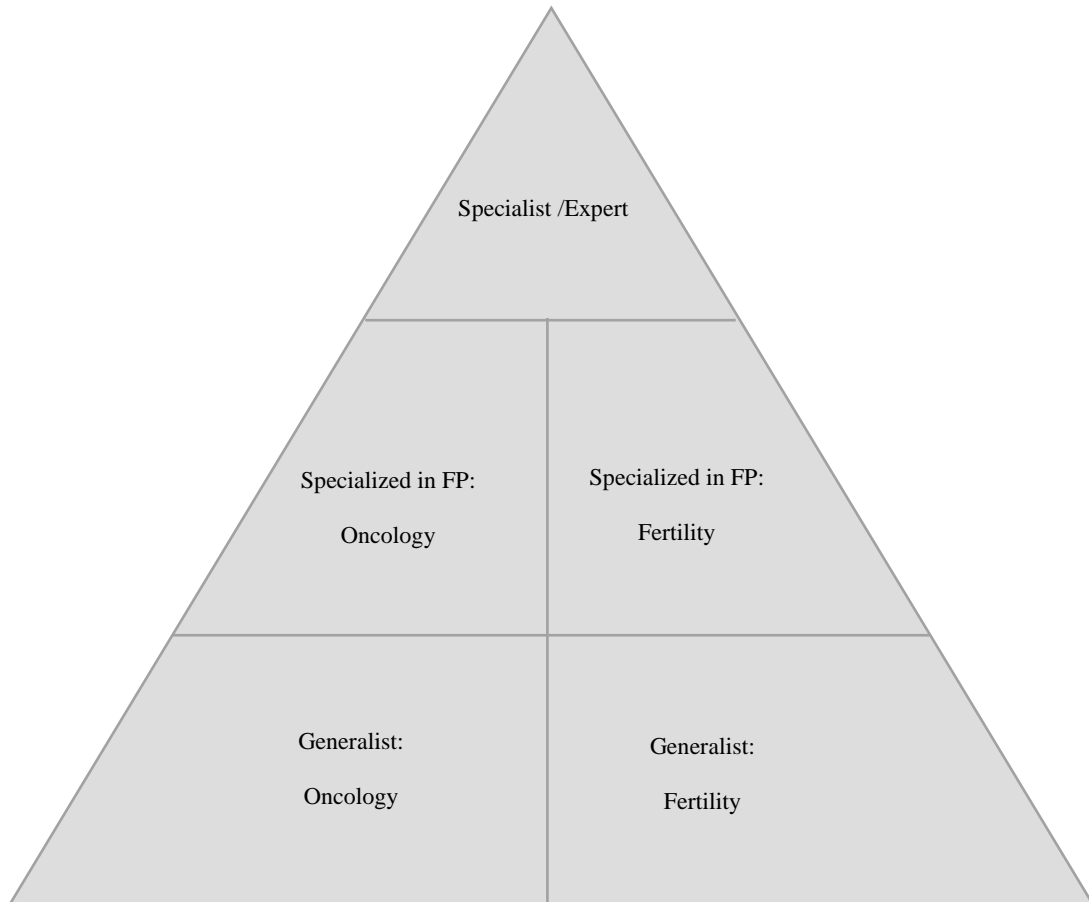
Yee, S., Buckett, W., Campbell, S., Yanofsky, R., & Barr, R. D. (2012). Women's health: A national study of the provision of oncofertility services to female patients in Canada.

*Journal of Obstetrics and Gynaecology Canada*, 34(9), 849–858.

[https://doi.org/10.1016/S1701-2163\(16\)35384-1](https://doi.org/10.1016/S1701-2163(16)35384-1)

Appendix A

*FP Nursing Competency Framework*



Appendix B

*Competencies*

<b>Expertise Level</b>	<b>Competencies</b>
<b>Specialist/Expert</b>	<ol style="list-style-type: none"> <li>1) Advocacy Leadership</li> <li>2) Systems Leadership: policies and procedures are clear including the referral process, and electronic charting is set up</li> <li>3) Education and training of staff and the development of appropriate written resources for staff and patients</li> <li>4) Forge collaborations with oncology and fertility</li> <li>5) Advanced Clinical Care Planning for more complex FP cases</li> <li>6) Scholarship/Research</li> </ol>
<b>Specialized in FP: Oncology</b>	<ol style="list-style-type: none"> <li>1) Oncofertility Specialist knowledge with more in-depth knowledge on fertility beyond the basic introductory reproduction to include FP procedure options, risks, and benefits, and FP into survivorship which may include knowledge on third party reproduction such as surrogacy</li> <li>2) Specialized training on patient decision aids and the decision-making process</li> <li>3) Communication on the cost of FP</li> <li>4) Ethical Considerations: posthumous reproduction, disposition of human reproductive material</li> </ol>
<b>Specialized in FP: Fertility</b>	<ol style="list-style-type: none"> <li>1) Oncofertility Specialist knowledge with more in-depth knowledge of cancer treatments and their specific levels of gonadotoxicity and their impact on ovarian reserve. Also included is knowledge on the utilization of cryopreserved gametes in survivorship</li> <li>2) Specialized training on patient decision aids and the decision-making process</li> <li>3) Communication on cost FP</li> <li>4) Ethical considerations: posthumous reproduction, disposition of human reproductive material</li> </ol>
<b>Generalist: Oncology and Fertility</b>	<ol style="list-style-type: none"> <li>1) Knowledge of referral pathways</li> <li>2) Provide written resources on FP to eligible patients</li> <li>3) Provide basic FP options and cost</li> <li>4) Identify if patients have reproductive concerns and psychosocial distress</li> <li>5) Specialized training on identifying when a referral is necessary for psychosocial counseling care</li> </ol>



	<ul style="list-style-type: none"><li>6) Oncology: Basic reproduction knowledge and FP options</li><li>7) Fertility: Basic cancer treatment regimens and FP options</li></ul>
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Appendix C

*Resources for the Fertility Preservation Nurse*

Courses	
	<p>Enriching Communication Skills for Health Professionals in Oncofertility (ECHO)</p> <p>ECHO is a web-based training program that includes psychosocial, biological, clinical and skill-building modules to help oncology health professionals communicate timely and relevant information regarding reproductive health to their adolescent and young adult (AYA) patients</p> <p><a href="http://www.rhoinsitute.org/">http://www.rhoinsitute.org/</a></p>
	<p>American Society for Reproductive Medicine (ASRM)</p> <ol style="list-style-type: none"> <li>1) Basic Infertility Course</li> <li>2) Nurse Certificate Course in Reproductive Endocrinology and Infertility</li> <li>3) Principles of Fertility Preservation for Reproductive Health Providers Certificate Course</li> </ol> <p><a href="https://store.asrm.org/Learn/FindACourse">https://store.asrm.org/Learn/FindACourse</a></p>
	<p>American Society of Clinical Oncology (ASCO)</p> <ol style="list-style-type: none"> <li>1) The Conversation: Fertility Preservation</li> <li>2) Implementing Fertility Preservation in Men</li> <li>3) Implementing Fertility Preservation in Women</li> <li>4) Implementing Fertility Preservation in Adolescent Females</li> </ol> <p><a href="https://elearning.asco.org/catalog?text=fertility%20preservation">https://elearning.asco.org/catalog?text=fertility%20preservation</a></p>
	<p>Canadian Association of Nurses in Oncology (CANO)</p> <ol style="list-style-type: none"> <li>1) Cancer 101 – Back to Basics</li> </ol> <p><a href="https://www.cano-acio.ca/page/pathway_webinars">https://www.cano-acio.ca/page/pathway_webinars</a></p>
	<p>The Ottawa Hospital – Patient Decision Aids</p> <ol style="list-style-type: none"> <li>1) Ottawa Decision Support Tutorial (ODST)             <ul style="list-style-type: none"> <li>- based on the Ottawa Decision Support Framework and designed to help health professionals further develop their knowledge and skills in providing decision support</li> </ul> </li> </ol> <p><a href="https://decisionaid.ohri.ca/training.html">https://decisionaid.ohri.ca/training.html</a></p>

Resources	
	<p>1) Canadian Fertility and Andrology Society (CFAS)</p> <p>Roberts, J., Tallon, N., &amp; Holzer, H. (2014). Fertility preservation in reproductive age woman facing gonadotoxic treatments: CFAS Clinical practice guidelines. Retrieved from <a href="https://cfas.ca/wp-content/uploads/2016/03/CFAS_CPG_Fertility_Preservation_2014.pdf">https://cfas.ca/wp-content/uploads/2016/03/CFAS_CPG_Fertility_Preservation_2014.pdf</a></p> <p>2) American Society for Reproductive Medicine (ASRM)</p> <p>The Practice Committee of the ASRM. (2019). Fertility preservation in patients undergoing gonadotoxic therapy or gonadectomy: A committee opinion. <i>Fertility and Sterility</i>, 112(6), 1022–1033. <a href="https://doi.org/10.1016/j.fertnstert.2019.09.013">https://doi.org/10.1016/j.fertnstert.2019.09.013</a></p> <p>3) American Society of Clinical Oncology (ASCO)</p> <p>Oktay, K., Harvey, B. E., Partridge, A. H., Quinn, G., Reinecke, J., Taylor, H., ... Loren, A. W. (2018). Fertility preservation in patients with cancer: ASCO clinical practice guideline update. <i>Journal of Clinical Oncology</i>, 36(19), 1994–2001. <a href="https://doi.org/10.1200/JCO.2018.78.1914">https://doi.org/10.1200/JCO.2018.78.1914</a></p> <p>4) Royal College of Nursing (RCN)</p> <p>Royal College of Nursing. (2017). Fertility preservation: Clinical professional resource. <a href="https://doi.org/10.1002/9781444393958.ch17">https://doi.org/10.1002/9781444393958.ch17</a></p> <p>5) The National Institute for Health and Care Excellence</p> <p>NICE. (2014). Cryopreservation to preserve fertility in people diagnosed with cancer. Retrieved from <a href="https://pathways.nice.org.uk/pathways/fertility/cryopreservation-to-preserve-fertility-in-people-diagnosed-with-cancer#content=view-node%3Anodes-providing-information-about-cryopreservation">https://pathways.nice.org.uk/pathways/fertility/cryopreservation-to-preserve-fertility-in-people-diagnosed-with-cancer#content=view-node%3Anodes-providing-information-about-cryopreservation</a></p> <p>6) Oncofertility Consortium</p> <p><a href="http://oncofertility.northwestern.edu/search/site/nurse">http://oncofertility.northwestern.edu/search/site/nurse</a></p> <p><a href="https://www.reproedia.org/">https://www.reproedia.org/</a></p> <p>7) The Ottawa Hospital Patient Decision Aids</p> <p><a href="https://decisionaid.ohri.ca/AZinvent.php">https://decisionaid.ohri.ca/AZinvent.php</a></p>

<b>Special Interest Groups</b>	<p>1) Canadian Fertility and Andrology Society (CFAS)</p> <ul style="list-style-type: none"><li>- Nursing Special Interest Group</li><li>- Fertility Preservation Special Interest Group</li></ul> <p><a href="https://cfas.ca/special-interest-groups.html">https://cfas.ca/special-interest-groups.html</a></p> <p>2) American Society for Reproductive Medicine (ASRM)</p> <ul style="list-style-type: none"><li>- Fertility Preservation Special Interest Group</li></ul> <p><a href="https://www.asrm.org/membership/asrm-member-groups/special-interest-groups/">https://www.asrm.org/membership/asrm-member-groups/special-interest-groups/</a></p>
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