

# Chapter 13

## Patient Navigation and Coordination of Care for the Oncofertility Patient: A Practical Guide

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### Introduction

Improved detection and treatment of cancer in reproductive-age patients has greatly improved the long-term survival of children and reproductive-age individuals with cancer. Hence, such treatments have made it possible for these individuals to consider their long-term health and happiness after cancer. For many, this includes having biological children. Various methods of fertility preservation are now available for both males and females. However, in order to maximize fertility preservation options available to patients facing imminent gonadotoxic therapies, it is critical that patients quickly access oncofertility care and that providers expedite fertility preserving strategies. Patient navigators and nurses play a critical role not only in coordinating initial consultations but also in shepherding patients through treatments that are often complex, invasive, stressful, and time consuming. This chapter will describe ways to improve the fertility preservation consult using teams of providers that are unified by allied health professionals, with special emphasis on the role of patient navigators and nursing in the care of the oncofertility patient.

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## Challenges to Providing Fertility Preservation Patient Care

### *Access to Care*

Despite growing support from the medical community, cancer patients' access to fertility preservation services remains limited [1], largely because oncologists do not routinely refer patients for consultation. Indeed, a recent study reported that only 47% of oncologists routinely refer cancer patients of childbearing age to a reproductive endocrinologist [2] even though most are aware that future fertility is important to these patients. In a recent 22-question survey that assessed pediatric oncology specialists' attitudes and practice patterns toward fertility preservation, the majority of respondents acknowledged that fertility threats are a major concern for patients and that all pubertal cancer patients should be offered a fertility consultation [3]. Moreover, while almost half of oncologists were familiar with the 2006 ASCO recommendations regarding fertility preservation, only 39% of health-care professionals said they utilize those recommendations to help with treatment decision making for their patients [3]. Reasons why oncologists may not routinely discuss fertility risks and options and refer patients include a focus on treating the disease itself; the perceived urgency of cancer treatment; the perception that limited proven options for fertility preservation exist, particularly for prepubertal patients and single females; the perception that fertility is not important to patients; and not knowing to whom to refer patients interested in fertility preservation [2, 4–6].

Nonetheless, while clinical judgment may be used to decide whether fertility preservation techniques are appropriate, referrals should still be made for patients to discuss the risks and options at the earliest possible opportunity. Cancer patients have a need for immediate consults, access to the entire menu of options, and contact with staff who can move quickly to make accommodations. If a referral is made soon after a cancer diagnosis, there is often a minimal time delay for that patient to begin their cancer therapy should they wish to pursue fertility preservation [7].

In developing an effective fertility preservation program for pediatric and young adult oncology patients, it is critical to create an interdisciplinary relationship between oncologists, reproductive endocrinologists, and urologists. A collaborative relationship will facilitate communication and the appropriate referral of oncofertility patients [8, 9]. As will be discussed in more detail below, establishing an oncofertility patient navigator position can significantly reduce the barriers between patients and specialists.

### *Cost*

Cost of fertility preservation is often a major barrier for patients to access these technologies. For males, the cost to bank sperm is often under \$1,000, including storage fees. There is minimal insurance coverage for cryopreservation of sperm.

Other methods such as testicular sperm extraction can be much more expensive due to the surgery required for the procedure. While cost can be a barrier for males, often, it is more so for females. The average out-of-pocket cost of in vitro fertilization (IVF) is \$12,500 in the United States [10]. Many infertility patients have saved for years in order to pursue their dream of biological parenthood. Cancer patients who wish to pursue fertility preservation do not have the luxury of this type of time to save money. While some states have infertility mandates on insurance coverage, this does not always apply to patients seeking fertility preservation. The current definition of infertility assumes that medicine is always reactive and does not acknowledge that it can be proactive by treating infertility before it occurs in the cancer patient [11]. Unfortunately, once a female cancer patient's ovarian reserve has been depleted by gonadotoxic therapy, assisted reproductive technologies may not be effective. Writing appeal letters to insurance companies can sometimes prove to be beneficial for patients. Sample letters and forms are listed on Northwestern's Oncofertility website for both providers and patients to access ([www.oncofertility.northwestern.edu](http://www.oncofertility.northwestern.edu)).

## **Improving Access to Fertility Preservation Care**

### ***Raising Institutional Awareness***

To access oncofertility care, patients must be first informed of the fertility risks associated with cancer therapies. However, ensuring that patients are being informed of the fertility risks and options at the time of diagnosis can be extremely difficult, since this is typically the responsibility of the treating oncology team. Raising institutional awareness of the potential gonadotoxicity of cancer therapies is therefore important and can be achieved in several ways. Institutional policies and procedures can be established so that patient education becomes a required part of the consultation and treatment consent process. Moreover, printed patient and physician materials (from organizations including Fertile Hope and The Hormone Foundation) should be available in oncology offices and can prompt a discussion. Printed informational materials can open the door for patients to begin learning more about how their cancer and subsequent cancer treatment will impact their fertility. There is also a need to improve educational materials on fertility preservation options. In one study, only 27.4% of oncology providers believed that the fertility preservation materials they provide to their patients are relevant to the specific cancer diagnosis [12]. There is also anecdotal evidence that patients often do not read the material they are given and that a conversation with their oncologist is crucial for patients to understand the gravity of infertility risk and the options for fertility preservation.

Electronic tools are available that can help coordinate oncofertility care and improve patient access to fertility preservation. At several institutions, electronic medical records can prompt the oncologist to discuss fertility risk and refer patients for consultation. At Northwestern, for example, during every young adult

new patient consult, the oncology provider is asked a series of questions regarding fertility preservation in the electronic medical record before he or she can close the encounter. These include:

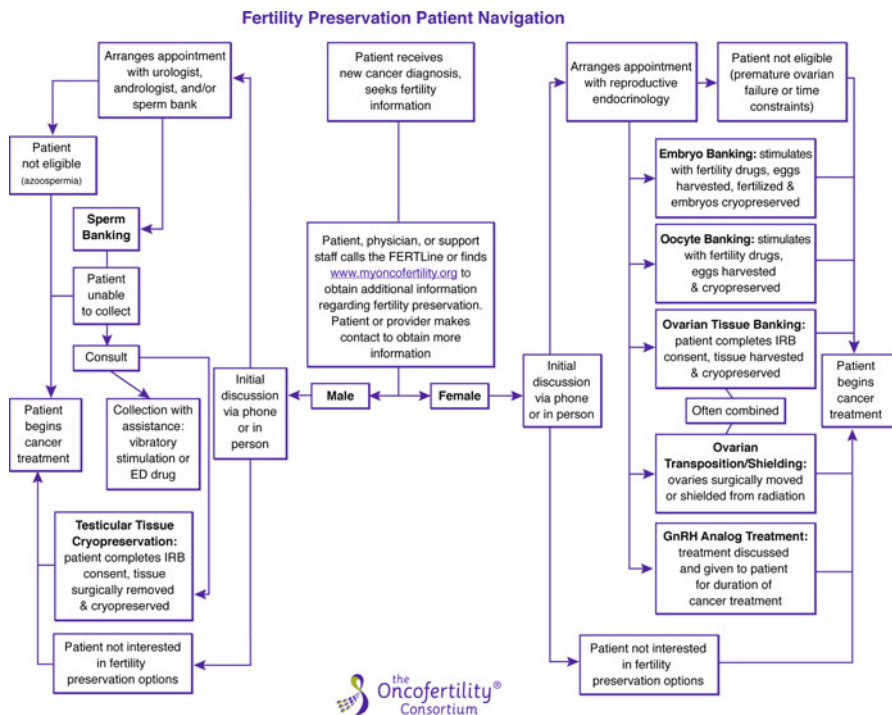
- Has the patient been informed about the impact their treatment may have on fertility?
- Is the patient interested in fertility preservation? (If so, the oncofertility patient navigator telephone number is provided so that a fertility preservation consultation can be arranged with a reproductive endocrinologist.)

Electronic medical records also make it possible for the oncofertility patient navigator or reproductive endocrinologist to receive regular reports of any reproductive-age patient who is to receive a fertility-threatening treatment or any patient with an interest in fertility preservation. The navigator or reproductive endocrinologist can then reach out to the oncologist to set up appropriate and timely consultations.

Other electronic resources have been developed to improve education and access to fertility preservation services at Northwestern and within the Oncofertility Consortium [13]. Several websites have been created that focus specifically on reproductive options for cancer patients, including [myoncofertility.org](http://myoncofertility.org), [fertilehope.org](http://fertilehope.org), and [savemyfertility.org](http://savemyfertility.org) (see Appendix for more online resources). Furthermore, a new iPhone App has been launched, *iSaveFertility*, which allows providers and patients instant access to fertility preservation information. The application also allows oncology professionals to directly email this information to their patients in English or Spanish. The website that serves as the launching point for this application, [www.savemyfertility.org](http://www.savemyfertility.org), also has patient fact sheets that are free for offices to print and hand out to interested patients.

## **The Role of Patient Navigators in Improving Fertility Preservation Patient Care**

Patient navigation in oncology has been broadly defined as “individualized assistance offered to patients, families, and caregivers to help overcome health care system barriers and facilitate timely access to quality health and psychosocial care, from prediagnosis through all phases of the cancer experience” [14]. This definition can be applied to patient navigation in fertility preservation as well. By serving as the primary contact for patients and clinicians, the patient navigator can facilitate a cohesive relationship between patients and the various health-care professionals that are involved in their care. Within the health-care setting, the oncofertility patient navigator bridges institutional and disciplinary boundaries so that cancer patients are able to receive timely information regarding fertility preservation options. This function of the oncofertility patient navigator makes it possible for patients to make well-informed decisions prior to the beginning of cancer treatment. Figure 13.1 demonstrates how the patient navigator serves a pivotal role in directing cancer



**Fig. 13.1** This flowchart demonstrates how the patient navigator serves a pivotal role in directing cancer patients toward fertility preservation services and summarizes available options for females and males

patients toward fertility preservation services and summarizes available options for females and males.

For example, at Northwestern, the oncofertility patient navigator carries a pager and is available 24-h a day to receive referrals for fertility preservation counseling. The navigator’s role is to make contact with the patient, collect important clinical information, and set up an appointment for fertility preservation counseling with a reproductive endocrinologist or urologist as appropriate. In addition, there is a 24-h telephone service called the Oncofertility FERTLINE where patients and providers can call one number to obtain free, individualized information and referrals for fertility preservation services. Often, nurses or social workers within the health system play a patient navigator role.

With a good referral system, oncology professionals do not need to become experts in fertility. The oncofertility patient navigator can shepherd patients between the complex specialties of oncology, urology, and reproductive endocrinology, as well as help make a complex topic more understandable and accessible to both clinicians and patients. The navigator can ensure that patients do not get lost between specialties.

In addition to facilitating consultation, navigators play other important roles. Navigators educate patients about available fertility preservation options and can direct patients to online educational resources described above such as [fertilityhope.org](http://fertilityhope.org), [savemyfertility.org](http://savemyfertility.org), and [myoncofertility.org](http://myoncofertility.org). As more and more educational materials become available, the oncofertility patient navigator is best able to sort through what is best for a given practice, deliver appropriate material to patients, inform program developers about unmet needs of the present materials, and help drive the next generation of web, print, and smartphone materials that are best suited for this patient cohort.

The oncofertility patient navigator can also provide important financial information and advice regarding fertility preservation procedures. Costs for fertility preservation services vary widely and often are not covered by insurance. A well-informed patient navigator who stays in touch with the patients can ensure that expectations regarding reimbursement are managed up front and that follow-up letters to insurers are provided. Cost is a big issue for young patients and physicians and their office staff may not have the capacity to work closely on the special needs of the cancer patients. Dedicated oncofertility patient navigators can provide the level of personalized care and interaction that these patients require. They may not be able to alter the payer decision, but they will provide the patient with the knowledge that everything that could be done was done to ease their financial burden. Navigators can also point patients to programs available to defray the costs of fertility preservation. For example, national organizations such as LIVESTRONG have partnered with pharmaceutical companies and reproductive endocrinology practices to bring affordable fertility preservation services to patients. In these arrangements, fertility centers agree to offer cancer patients heavily discounted IVF cycles, and pharmaceutical companies provide patients fertility medications at no cost. This can result in thousands of dollars of savings and put fertility preservation within a patient's financial reach.

## **Ensuring the Reproductive Endocrinology Practice is Equipped to Care for Oncofertility Patient Referrals**

After a patient has been referred to a reproductive endocrinologist, it is critical that the fertility center is equipped to care for the patient. Given the urgency of cancer treatment, time can be a major limiting factor for a patient recently diagnosed with cancer to undergo fertility preservation procedures. Therefore, it is essential that the reproductive endocrinology office be able to accommodate these patients for consultation and treatment as soon as possible after the referral is made (ideally within a few days to a week). In order to accommodate oncofertility patients adequately, the office must have an "all hands on deck" approach. The clinical and laboratory staff must be immediately available to provide a full range of fertility preservation options for males and females. Because oocyte and embryo cryopreservation generally require timing with the start of a patient's menstrual cycle, the office must provide services year round.

After the referral, an urgent consult with the reproductive endocrinologist is the first step in considering fertility preservation options. Risk, success rates, and costs of standard and experimental fertility preservation options should be discussed with patients. In addition, disposition of gametes and tissues should be addressed. This process can be very overwhelming for the patient, as they are often still processing a recent cancer diagnosis and deciding on treatment. Unfortunately, patients must make a decision quickly about whether or which fertility preservation option they would like to pursue. A consultation with a mental health professional should be encouraged to assist in the decision-making process. Ideally, the mental health provider has experience with this patient population and can help to address their many and unique psychosocial needs and ensure that an adequate support system is available to them. Financial consultation is also a critical piece of oncofertility counseling since cost and coverage vary widely and may influence the decision to pursue fertility preservation treatments.

Because of the sensitive and urgent nature of oncofertility care, we recommend a team approach to patient counseling [15, 16]. Ideally, if time permits, patients meet with physicians, nurses, and mental health professionals in order to discuss fertility preservation options over several visits. In addition, electronic patient education tools such as myoncofertility.org can help patients in their decision-making process [17]. This approach can allow for a more comprehensive understanding of the psychosocial and medical needs of each patient and assist patient decision making.

### ***The Role of the Clinical Nurse Coordinator***

The oncofertility nurse coordinator plays a critical role in the care of oncofertility patient who decides to pursue oocyte or embryo cryopreservation. She/he provides patients with detailed instructions and extensive support during fertility treatment. Patients are in close contact with their oncofertility nurse coordinator before and during the process of ovarian stimulation to optimize outcomes. The first encounter with the nurse may be at the time of the physician consultation or shortly thereafter. The most important detail is the timing of stimulation, which often must be coordinated with other tests and procedures related to the cancer diagnosis. A consultation with the nurse is necessary to review the process of ovarian stimulation in detail and prepare the patient appropriately. While the physician may have covered many of these topics, it is important for the nurse to review them again as patients may not retain much of the information provided initially. Information to be covered in the consultation is listed in Table 13.1. Unlike infertile couples pursuing IVF, oncofertility patients often have little or no knowledge about the process of ovarian stimulation and usually have no experience administering injections. The process may be overwhelming especially in the setting of a new cancer diagnosis. Having a support person available for the consultation can be extremely helpful. In addition, frequent contact with the clinical nurse can help patients navigate the process more easily.

**Table 13.1** Information to be reviewed at the time of the clinical nursing consultation

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<ul style="list-style-type: none"> <li>• Facilitate communication           <ul style="list-style-type: none"> <li>◦ Document patient contact information</li> <li>◦ Provide clinic contact information for easy access (i.e., direct phone number, cell phone, e-mail)</li> </ul> </li> <li>• Provide information regarding office and lab locations and hours           <ul style="list-style-type: none"> <li>◦ Weekday and weekend schedules</li> </ul> </li> <li>• Review protocol and IVF procedures           <ul style="list-style-type: none"> <li>◦ Hormone treatment procedure and schedule</li> <li>◦ Egg retrieval procedure, anesthesia, and recovery time</li> <li>◦ Discussion of ovarian hyperstimulation syndrome symptoms and management</li> </ul> </li> <li>• Review the medications to be used during the IVF cycle and their side effects</li> <li>• Review pharmacy information and prescription coverage</li> <li>• Provide patient-specific protocol injection training           <ul style="list-style-type: none"> <li>◦ Demonstration of injection administration, using multimedia resources including the Internet, DVDs, and handouts</li> </ul> </li> <li>• Review mapping/calendar           <ul style="list-style-type: none"> <li>◦ Review the patient's menstrual cycle and when they should be starting stimulation. Discuss any conflicts in the schedule such as other doctor appointments, work schedule, and planned vacations</li> </ul> </li> <li>• Discuss cycle monitoring           <ul style="list-style-type: none"> <li>◦ Counsel the patient on the need for frequent visits for ultrasounds and hormone analysis during treatment</li> <li>◦ Explain that they may see multiple doctors/nurses/ultrasound technicians, and this is a brief visit to gather information about their cycle. The entire process can take a few weeks, and it is best to minimize stress by managing the patient's expectations</li> </ul> </li> <li>• Review prescreening labs           <ul style="list-style-type: none"> <li>◦ Prescreening blood work for infectious diseases is required prior to oocyte retrieval. Some centers may choose to do FDA-required blood panels for female and male partners in the event that the patient may need to use a gestational carrier in the future. These labs must be drawn at a facility that provides FDA-approved testing for low prevalence populations</li> </ul> </li> <li>• Ensure that medical testing is completed           <ul style="list-style-type: none"> <li>◦ Semen analysis to determine the need for intracytoplasmic sperm injection (ICSI)</li> <li>◦ Blood work to determine ovarian reserve (follicle-stimulating hormone [FSH], estradiol, anti-Müllerian hormone [AMH])</li> </ul> </li> <li>• Ensure IVF and cryopreservation consent forms are signed</li> <li>• Help schedule financial counseling           <ul style="list-style-type: none"> <li>◦ The patient must meet with the financial counselor to discuss financial obligations, any insurance coverage that can be utilized, and application to the Sharing Hope program (see Appendix for more information)</li> </ul> </li> </ul>
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### ***The Role of the Research Nurse Coordinator***

Like the clinical nurse, the oncofertility research nurse coordinator plays a critical role in the care of oncofertility patients who decide to pursue investigational fertility preservation options. For oocyte cryopreservation, the clinical nurse and research nurse work hand in hand to coordinate ovarian stimulation and to make sure that patients are



aware of the experimental status of oocyte cryopreservation. It is important to ensure that informed consent is obtained from all patients cryopreserving oocytes. For other investigational procedures, like ovarian and testicular banking, the research nurse generally takes a lead role in coordinating patient care. The patient should meet with a research coordinator to review consents and study procedures. When caring for minors, both a patient assent and the legal guardian's consent may be required. It is necessary to coordinate preoperative testing, serologic testing for tissue storage, and surgical scheduling in relation to planned cancer therapies. While scheduling surgeries in the morning is ideal so that laboratory staff can be available during normal working hours to process and preserve tissue, it is often not possible. The nurse typically transports the tissue from the surgical suite to the laboratory for processing and cryopreservation. Any research tissue is prepared and sent to the research laboratory according to the specific protocol in place.

### ***Laboratory Requirements***

The laboratory in the reproductive endocrinology practice should be adequately trained in male and female fertility preservation techniques and be available to perform a full complement of these procedures year round. Some centers have “down cycles” or times when the laboratory is not performing services. When a clinical practice makes a commitment to take care of oncofertility patients, however, it is important that the lab be open and available to accommodate these cycles 7 days a week. With respect to ovarian and testicular tissue processing and cryopreservation, the laboratory may need to be available after normal hours in cases where surgery cannot be performed in the morning.

### ***Donor Sperm***

For women who wish to bank embryos without a committed sexual partner, donor sperm must be acquired. It is generally recommended that sperm be obtained from a commercial sperm bank, where donors are tested according to the FDA standard (with quarantine of sperm for 6 months and retesting of the donor). These can be accessed online so that a sperm donor can be chosen as soon as possible and sperm shipped to the laboratory prior to the oocyte retrieval. The patient will need to sign a consent for using donor sperm and have appropriate FDA screening blood work performed. The clinical nurse usually coordinates serologic testing and shipment of sperm to the laboratory. Sometimes female patients wish to use sperm from someone they know but with whom they are not intimate. This is usually not recommended for oncofertility patients because there is insufficient time to quarantine the sperm and retest the donor to ensure that the sperm is safe.

## ***Legal Consultation***

In unmarried, sexually intimate couples banking embryos, the legal status of the embryos may be problematic if the couple separates in the future ([18–21]; also see Chap. 9 in this volume). Usually consent is required from both partners in order to use the embryos to achieve pregnancy. Therefore, it is recommended that couples seek legal counsel before or after the embryos are created to discuss embryo ownership and future use. It is important to recognize that reproductive legal practices vary by state.

## **Conclusion**

While more fertility preservation options now exist for reproductive-age cancer patients, access to these services continues to be limited to a few academic centers. There are a tremendous number of individuals—patients, specialists, and consultants—who must be coordinated in order to move a patient from cancer diagnosis to completion of fertility preservation in a short period of time. Access to a fertility preservation center can be improved through oncologist and patient education, via electronic tools and through active patient navigation. Reproductive endocrinology practices that receive oncofertility referrals must be equipped to provide a full range of options on short notice. Coordination of care demands a team effort, involving physicians, nurses, mental health professionals, office staff, and laboratory personnel. While caring for oncofertility patients can be challenging, helping patients navigate fertility preservation options can be incredibly gratifying because it gives patients some control over their reproductive options and provides hope for the future. Expanding the patient navigator model to all comprehensive cancer centers (academic and community based) over the next 5–8 years will ensure that all patients are provided information about their fertility regardless of geography.

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