

# Developing a Referral System for Fertility Preservation Among Patients With Newly Diagnosed Cancer

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## Key Words

Oncology care setting, fertility preservation, reproductive concerns, patient-physician communication

## Abstract

The goal of this project was to develop a referral system to increase the likelihood that patients of childbearing age with newly diagnosed cancer receive timely information about fertility, and reduce the burden oncologists may feel when discussing and exploring fertility preservation options with their patients. The group developed and examined the effectiveness of a fertility preservation referral system through pilot-testing a developed patient education brochure. During the 12-month pilot-testing period, 776 patients of childbearing age (< 40 years) were seen at H. Lee Moffitt Cancer Center and 349 brochures were taken. The reproductive endocrinologist/infertility clinic experienced a 9-fold increase in the number of calls received during the 12-month study period, with 122 calls received compared with 13 the prior year. The large increase in calls illuminates the gap in patient interest and referral, and shows an effective method to transmit this information. Improving the communication of time-sensitive information about fertility and preservation options to patients with cancer is associated with an increased likelihood of improving quality of life, reducing patient distress, and increasing use of ancillary fertility-

related health services. Through referring and providing patient information, this referral system allows oncologists to fulfill their obligation and make informed decisions about fertility preservation, thereby improving the full cancer care continuum. (*JNCCN* 2011;9:1219–1225)

In the United States, more than 72,000 adolescents and young adults (ages 15–39 years) are diagnosed with cancer each year.<sup>1</sup> Fortunately, advancements in early detection and treatment mean many young patients with cancer will live well beyond their cancer diagnosis. As higher rates of cancer survivorship are reached, the clinical focus has shifted from survival alone to include long-term quality-of-life issues.<sup>2</sup> One important quality-of-life issue in young patients is the potential infertility caused by some cancer treatments.<sup>3,4</sup> The likelihood of infertility varies according to age at diagnosis, cancer site, treatment modality, treatment agent, and other factors<sup>5</sup>; however, sustained infertility is estimated to develop in 50% to 95% of cancer survivors treated during their reproductive years.<sup>5–8</sup>

The issue of fertility subsequent to cancer treatment is a primary concern for most patients of childbearing age.<sup>9,10</sup> Even in the face of a life-threatening illness, patients report that the loss of fertility is almost as distressing as the actual battle with cancer.<sup>11,12</sup> Several studies have found that most cancer survivors (~ 76%), men and women alike, are interested in having children, especially if they were childless at diagnosis.<sup>10,13–15</sup> In fact, many patients report that their cancer experience increased the value they placed on parenthood and family ties.<sup>16,17</sup>

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The long-term negative impact of infertility has also been shown among young male and female cancer survivors.<sup>18,19</sup> More-recent studies suggest that among young women in particular, cancer-related infertility is associated with a greater risk for emotional distress and poorer quality of life.<sup>20,21</sup> However, options are available that may preserve the ability to have biological children in the future.

## Fertility Preservation Options

Although the physiologic impact on the patient's fertility may be inevitable, the practical outcome—the ability to later have biological children—might be improved by recent advances that allow fertility preservation (FP) options for both male and female patients with cancer.

FP methods that are considered established are sperm cryopreservation for men and embryo cryopreservation for women.<sup>5</sup> These options must be started before treatment. In some cases these treatments are not suitable and experimental options may be considered, such as hormonal gonadoprotection for men and oocyte cryopreservation, ovarian transposition, ovarian downregulation (suppression), and ovarian tissue cryopreservation for women, and gonadal shielding for both men and women.<sup>5</sup> A specialist can help patients decide which FP option is best in a particular circumstance.

## Lack of Knowledge as a Barrier

Unfortunately, patients with cancer may not be aware of their fertility risk and FP options within the limited timeframe in which these options are available. A pilot study<sup>13</sup> and a follow-up study<sup>14</sup> showed that patients are not well informed about available FP options. Among cancer survivors who were queried about whether a health care provider had discussed the risk of infertility with them, only 50% recalled this occurrence.<sup>22</sup> In a study of female patients alone, fewer than 35% recalled discussing the risks of infertility with a health care provider during or after cancer treatment.<sup>16</sup>

## The Importance of Physician Endorsement

Although advocacy organizations, such as Fertile Hope, have been proactive in making resources related to FP available to patients with cancer and

their families, research shows that patients may perceive information provided by national organizations to be a resource but not necessarily a course of action suggested for their situation.<sup>17</sup> Instead, receiving tailored information about cancer-related support services has been shown to help patients and families recognize that the service provided is endorsed by their physician.<sup>23</sup> Furthermore, patients report higher levels of satisfaction with integrative medicine referrals when a system is in place for receiving referrals and services and that suggests that these services are endorsed by their treating physician.<sup>24</sup>

## Guidelines

In acknowledgement of these findings, the ASCO (2006) and the American Society for Reproductive Medicine (2005) guidelines, and advocacy organizations such as American Cancer Society and Fertile Hope (now part of the Lance Armstrong Foundation), recommend that patients with newly diagnosed cancer receive risk information and a referral to a reproductive endocrinologist/infertility (REI) specialist. REI and associated clinics offer counseling and FP services tailored to individual patients with consideration of age, cancer type and stage, and the therapeutic agent recommended for treatment. In addition, these specialists can assess each patient's risk for infertility, reproductive capacity, and physical health to determine which FP options are available and likely to be successful.

Despite these recommendations, a 2008 national study of oncologists showed that fewer than 50% routinely refer patients to an REI specialist.<sup>25</sup> Studies of pediatric and adult oncologists examining referral practice patterns for fertility have found that a lack of resources regarding where or how to refer patients is a significant barrier and deterrent to discussion.<sup>26</sup> Several large studies have found that physicians are more likely to make appropriate referrals (e.g., for palliative care) when they practice within a system that has established guidelines and processes for referrals.<sup>27–31</sup> Furthermore, according to Fertile Hope, two-thirds of physicians would be more likely to discuss FP if detailed patient education materials and appropriate referrals were available.<sup>32</sup>

## Fertility Preservation Referral System

## The Moffitt Referral System

To improve patient awareness of FP services and reduce the burden on oncologists of discussing and referring for a service for which they may have limited training and time, the authors' group developed a 5-step system to ensure that all patients of childbearing age received a referral to an REI (Figure 1). The goal in building a referral system at H. Lee Moffitt Cancer Center was to effectively inform patients and direct them to services, and to minimize the direct burden on their oncologists. This integrated, coordinated system was based partly on the guidelines established by the Fertile Hope organization ([www.fertilehope.org](http://www.fertilehope.org)) for receipt of the Center of Excellence award.

### Methods

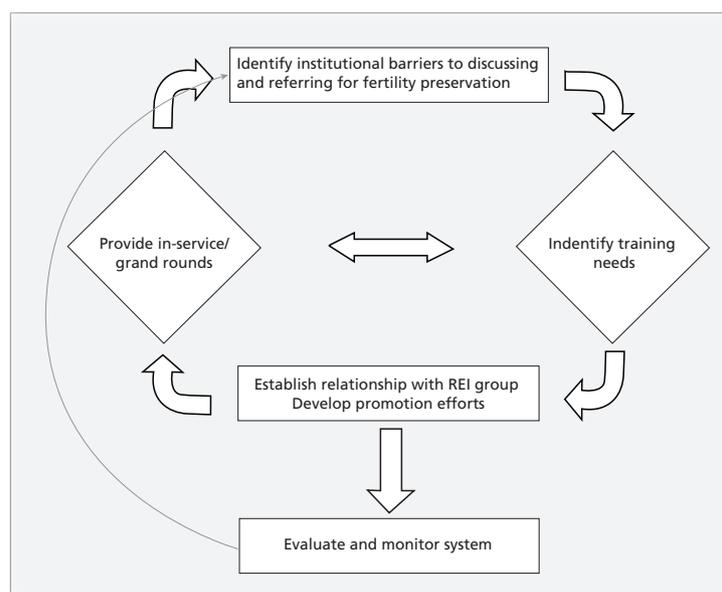
**Step One:** The first step in this process was to identify the institutional barriers to communicating with patients about FP options. The authors' group conducted a series of individual interviews with oncologists from each of the hospital clinics, and focus groups consisting of nurses and social workers. The primary barriers identified were lack of knowledge about need for FP, lack of awareness about where to refer patients, lack of knowledge of FP options, and a lack of time for these discussions.

**Step Two:** The authors' group conducted a series of in-service educational programs and Grand Rounds to educate health care professionals about the physi-

ologic effects of cancer treatment on reproductive capacity in patients of childbearing age and about the psychological importance of informing patients and offering referrals for additional information.

**Step Three:** The authors' group established a relationship with the University of South Florida In Vitro Fertilization (USF IVF) program ([www.usfivf.com](http://www.usfivf.com)) to create a referral process. This partnership was enhanced by Moffitt's relationship with these reproductive endocrinologists who specialize in FP for patients with cancer and their ability to implement a fee structure that provides at least a 50% reduction in the standard cost of these procedures. The clinic's participation in Fertile Hope's Sharing Hope program allows for the reduced fees and other services offered at deeply discounted rates. Additionally, REI specialists from USF IVF will also travel to Moffitt for inpatient consults.

Together with USF IVF, the authors' group developed a brochure for treating physicians to provide patients, which highlights the importance of discussing the effect of cancer treatment on fertility and reproduction, and directs patients to call or ask for assistance from the clinic nurse to schedule a phone or in-person consultation with an REI specialist. (To view the brochure, visit [www.insidemoffitt.com/Fertility-Preservation-What-You-Can-Do.htm](http://www.insidemoffitt.com/Fertility-Preservation-What-You-Can-Do.htm).) A unique telephone number was established for patients treated at Moffitt, which guarantees a return



**Figure 1** Flowchart of 5-step process.  
Abbreviation: REI, reproductive endocrinologist/infertility.

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phone call by an REI specialist within 24 hours and an appointment, if desired, within 48 hours.

**Step Four:** The authors' group conducted a pilot study at Moffitt. All clinic sites were included except for Senior Adult and Thoracic, because they do not see patients of reproductive age. The sarcoma clinics' staff (selected because they see the highest number of young men and women of reproductive age) were administered a pretest about current practices regarding discussion of fertility and referrals, and preferences for communication channels and information type. The process and brochure were modified based on the results of this pretest (Figure 2) and regular biweekly meetings to review the referral process. These modifications included the need for the brochure to deemphasize a discussion with the oncologist and place emphasis on a consultation with an REI specialist, and to make the phone system more patient-friendly.

The brochure was also tested with a small group of 5 survivors receiving follow-up care in the clinic. The authors' group received a waiver of need for consent from Moffitt's Institutional Review Board because they were not collecting any patient data and were asking for feedback to improve an educational resource. The patients suggested that emphasis on the window of opportunity to pursue FP options needed to be stronger, how FP services coordinated with oncology care services was not clear, and assurance should be given that patients' oncologist supported this consultation with an REI specialist.

The authors' group developed a call log with the USF IVF clinic to document calls, capturing information including patients who called from all clinics in the institution, the clinic or referring physician, patient gender, and type of service requested (phone, in-patient, or office consult). This reporting system was augmented by documentation of the disposition of the call (e.g., REI-provided phone consult, patient request of clinic consult after phone call, in-patient consult, office consult, cancellation, no-show).

**Step Five:** Two questions were added to the electronic patient health questionnaire, an electronic medical record completed by all new patients. Patients are asked, "Do you have all the children you wish to have? Yes/No"; "Would you like a referral to an infertility specialist? Yes/No" (Figure 3). The electronic patient questionnaire generates a report for the physician, and the response of "Yes" to either

of these questions is noted in the report. This serves as a prompt for the physician to distribute a brochure to the patient during the initial visit. It is Moffitt's policy for a patient to receive a brochure if they selected "Yes."

## Results

From August 2007 to August 2008, before this pilot study was initiated, the USF IVF program received a total of 13 calls and referrals from Moffitt patients and physicians. After initiation of the study, from October 2008 to September 2009, the authors' group monitored the brochure quantities distributed to the breast, gastrointestinal, genitourinary, gynecologic, head and neck, hematology, neurology, and sarcoma clinics. The brochure was distributed with other clinic materials in the patient waiting areas of these 8 clinics. Results of the study showed that 776 patients of reproductive age (< 40 years) were seen in these clinics over the 12-month period; a total of 349 brochures were taken from these waiting rooms (although whether patients took multiple copies could not be determined) and 122 phone calls were placed by patients (or their nurses) to the USF IVF clinic. Therefore, approximately 16% of patients of reproductive age contacted the REI group. Of these calls, 77 patients wanted only to speak to an REI specialist over the phone, 45 scheduled an appointment, 38 attended an outpatient appointment, 3 were no-shows, and 4 were inpatient consults (i.e., the patients were hospitalized at Moffitt). Of the 42 attended appointments, 11 male patients chose to bank sperm (including 3 inpatients), 12 female patients chose oocyte preservation, 10 female patients chose embryo cryopreservation, and 7 female and 2 male patients opted for no services. Thus, a 12-month pilot of the brochure and referral system increased calls and consults to the REI by 9-fold.

## Discussion and Conclusion

The goal of the Moffitt Referral System is to develop a structure that enhances patient quality of life and satisfaction through empowering patients to make fertility-related decisions based on relevant and timely information, and to provide patients the chance to be active in deciding whether to act.<sup>33</sup> The 12-month pilot program showed that 16% of the eligible population is contacting the REI group for a consult, and 27% of these patients are opting

## Fertility Preservation Referral System

### Knowledge of Fertility Preservation

Please circle the response that best describes your level of agreement with the statement.

1. Alkylating agents have been linked to infertility in cancer patients.

1	2	3	4	5
Strongly agree	Agree	Not sure	Disagree	Strongly disagree

2. Abdominal and pelvic radiation have been linked to infertility in cancer patients.

1	2	3	4	5
Strongly agree	Agree	Not sure	Disagree	Strongly disagree

3. Some cancer treatments can cause early menopause in females.

1	2	3	4	5
Strongly agree	Agree	Not sure	Disagree	Strongly disagree

4. In general, the risks of infertility after cancer are higher in men than women.

1	2	3	4	5
Strongly agree	Agree	Not sure	Disagree	Strongly disagree

5. Sperm banking, embryo cryopreservation, and oophoropexy are the only established methods of fertility preservation.

1	2	3	4	5
Strongly agree	Agree	Not sure	Disagree	Strongly disagree

How commonly do the following barriers regarding fertility preservation occur in your practice?

1. A patient is too ill to delay treatment to pursue fertility preservation.

1	2	3	4	5
Always	Often	Sometimes	Rarely	Never

2. A patient cannot afford fertility preservation.

1	2	3	4	5
Always	Often	Sometimes	Rarely	Never

3. A patient does not want to discuss fertility preservation.

1	2	3	4	5
Always	Often	Sometimes	Rarely	Never

4. There is no place/person to refer my patients to for fertility preservation.

1	2	3	4	5
Always	Often	Sometimes	Rarely	Never

5. Time constraints affect my ability to discuss fertility preservation.

1	2	3	4	5
Always	Often	Sometimes	Rarely	Never

6. The primary barrier to discussing fertility preservation with patients of childbearing age is: (choose only one)

- My typical patient is too ill to delay treatment.
- Patient cannot afford fertility preservation.
- I do not have information to give my patients about fertility preservation.
- There is no place/person to refer my patients to.
- Time constraints.
- Patients do not want to discuss fertility preservation.
- No barriers.
- Other, please specify: \_\_\_\_\_

Figure 2 Pretest questions.

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**Fertility Preservation**

MediKiosk CANCER CHECK-IN

**Please complete the following form and touch "NEXT SCREEN" when complete.**

**The treatments you may receive for your health issue may impact your fertility. This varies depending on the type of treatment you receive. You should discuss fertility concerns with your health care providers. Are you considering having a child/children in the future? Please select one response.**

Yes   
  No   
  Not sure   
  I need help answering question

**Would you like to discuss fertility-related issues with a specialist? Please select one response.**

Yes   
  No   
  Not sure   
  I need help answering question

← PREVIOUS SCREEN
NEXT SCREEN →

**Figure 3** Electronic patient health questionnaire.

to pursue some form of FP. The authors acknowledge that the rates of FP uptake seem to be lower than those found in other studies<sup>34</sup>; however, the purpose of this article is to describe a system designed to keep patients well informed, rather than promote uptake of FP services. Additionally, anecdotal information from the REI clinic and Moffitt physicians suggests that some patients may not fully comprehend the “window of opportunity” for pursuing FP, despite the emphasis in the brochure. Patients report being “too overwhelmed” at the time of diagnosis and treatment planning to consider future childbearing goals, although multiple studies suggest survivors experience remorse and regret for not considering fertility issues when they had the opportunity.<sup>13,14,35–37</sup>

Furthermore, nurses and social workers at Moffitt suggest that the brochure helps some patients receive the information they need to feel certain that future childbearing is not a goal for them. Staff members suggested that the brochure facilitates conversations in which patients report, “I did not plan on having any more children” or “I’ve never wanted children.” Thus, the brochure can be perceived as effective in helping inform these patients about potential infertility from cancer treatment, even though, in keeping with their own goals, a consultation with an infertility specialist may not be required.

Providing timely and relevant information related to FP and the opportunity for a referral to an

REI specialist for consultation may reduce emotional distress and improve quality of life for patients as they transition from patient to survivor. Results from the pilot study illuminated the concept that a great need exists to ensure that all patients are aware of the window of opportunity for taking steps to preserve fertility. As a result of the pilot study, 2 questions were added to the electronic patient questionnaire prompting physicians to provide brochures directly to appropriate patients. Future plans include having an on-site clinic with a reproductive endocrinologist, and the opportunity for patients to have this consultation at the same time and place as their cancer care services is anticipated to increase consultation rates.

Oncologists often have limited time and expertise to discuss FP with patients, particularly in the context of each patient’s unique medical and social history. Furthermore, FP is evolving as a critical branch of reproductive medicine, with recent advances occurring at an accelerated pace. Thus, a streamlined referral system with aids, such as the health questionnaire and brochure the group developed, along with the involvement of reproductive medicine specialists, will help oncologists meet this obligation. Cooperation from the treatment team is imperative for the referral system’s success, and Moffitt’s system can serve as a model that can be standardized at other institutions. Staff at varying clinics

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within the hospital must be informed of the referral system and educated on resources and where to direct patients for the system to operate at its full potential. Through referring patients for consultation and providing them with the information required to make informed decisions, health care teams are afforded the opportunity to participate in a movement to empower patients through information.

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