

Chapter 11

Communication Between Oncofertility Providers and Patients

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Fertility Concerns Are Significant for Young Cancer Patients

Reproductive-Age Females

Even with all of the stresses that come with a new cancer diagnosis, such as understanding the chances of survival, impending treatments, financial burdens, and familial and work obligations, many young people diagnosed with cancer have significant concerns about their future fertility. In fact, among young women with cancer, concerns about children and family are second only to fears of cancer recurrence and an uncertain future [1]. A study by Partridge et al. asked 657 women under the age of 41 years at the time of diagnosis with breast cancer to complete a web-based survey about fertility issues [2]. More than half (57%) of young women with breast cancer recalled substantial having concerns about future infertility, and univariate analysis revealed several variables that were associated with increased concern about future fertility (Table 11.1). In multivariate analyses, a greater concern about fertility was associated with a desire to have more children, the prior number of pregnancies, and a history of difficulty conceiving. While some studies have asked patients about “fertility concerns” in general, others have narrowed down the issue to focus on specific questions that are commonly mentioned. For example, Thewes et al. identified the most common specific fertility questions that plague breast cancer patients (n=228) and the frequency at which these questions are satisfactorily addressed (Table 11.2) [3].

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Table 11.1 Variables associated with an increased concern about future fertility in women younger than 41 years with a diagnosis of breast cancer (n=657) [2]

Table 11.2 Top ten most common fertility-related questions asked by women with a diagnosis of cancer and whether they were answered satisfactorily (n=228) [3]

Question	Question was answered (%)	Question was not answered (%)
What should I be doing about contraception?	47	17
Am I currently fertile?	42	25
Am I going to be able to become pregnant after treatment?	42	13
What are the risks/benefits of having a child after cancer?	18	34
How long after treatment can I check whether I am still fertile?	17	31
What has happened to other breast cancer survivors who have decided to have children?	19	30
Are there any healthy concerns for children I might have in the future, as a result of my treatment?	13	29
If I become infertile, does it happen immediately?	23	29
What are the statistics about my chances of becoming pregnant?	28	24
Would a future pregnancy influence my prognosis (chance for recurrence)?	26	26

Fertility concerns can have a substantial impact on patients, both at the time of diagnosis and for years to come. Cancer survivors recall that fertility concerns can be influential enough to alter their cancer treatment decisions [2, 4]. Several studies have indicated that cancer survivors who are infertile due to their treatments are more likely to have emotional distress [2, 5, 6]. On a related note, there is a theoretic risk of medicolegal settlements in cases where patients feel that fertility preservation was not adequately addressed prior to the start of cancer treatment.

Reproductive-Age Males

Men also have fertility concerns at the time of cancer diagnosis and during the survivorship stage. In one survey (n=132), 76% of childless reproductive-age cancer

survivors report that they would like to have children in the future and only 6% of childless survivors state that having cancer decreased their desire for future children, with no significant difference in responses between genders [5]. Many men report that sperm cryopreservation prior to chemotherapy helped them in their emotional battle against cancer [7], though one study in 1999 found that only 8/43 (19%) male survivors had banked sperm before undergoing cancer treatment [5].

Children and Parents

There are added complexities when considering fertility preservation treatments for children with cancer, specifically when teasing out the desires of the child versus those of the parents. Parents consider the future quality of life for their child when pondering the issue of fertility preservation [8]. However, parents can have a range of opinions about the participation of their child in the decision-making process, with some parents feeling that the child should ultimately decide about fertility preservation, and others wanting more control about what is discussed with their child [8]. There is a dearth of qualitative data about the views of adolescents and prepubescent children on fertility preservation.

Are We Successfully Addressing Patients' Concerns About Fertility?

Oncology Providers

While it is clear that many patients have questions and concerns about future fertility, unfortunately, studies have shown that these needs are not adequately addressed in a significant percentage of patients. Admittedly, the time around the initial diagnosis of cancer is a stressful time for patients, families, and providers, and discussions about cancer diagnosis, acute risks, prompt treatment, and survival often take priority (see Chap. 8 in this volume for a discussion of this topic). Accordingly, studies have shown that many oncology professionals are not routinely discussing fertility with their reproductive-age patients [9–11]. A 2009 survey (n=613) found that 47% of responding oncologists routinely refer patients for fertility preservation counseling and that female physicians and those who had a favorable attitude about fertility preservation were more likely to refer [11]. Similarly, a 2010 survey of 249 oncologists found that more than half rarely refer patients to a fertility specialist, though 82% have referred patients at some point [12]. When planning cancer treatments, 30% state that they rarely consider a woman's desire for fertility [12]. Another study prospectively asked pediatric oncologists in the United Kingdom to complete a form after seeing individual patients about risk to fertility and options

for fertility preservation [9]. The possible impact of cancer treatments on fertility was discussed in 63% of cases ($n=648/1030$) and was more likely in cases involving male patients and those who were postpubertal (vs. prepubertal). By comparison, only 1% of girls (4/463) were referred to fertility centers. Other members of the oncology team could potentially take the lead in discussions about fertility; one qualitative study found that oncology nurses believe that discussing fertility with patients is part of their role, but most were not routinely having these conversations [13]. If the oncology team does not mention fertility concerns, patients may not know how or when or with whom to broach this topic.

There are many proposed factors that may inhibit the oncology team from adequately discussing fertility concerns with patients, including provider-related issues (deficiency in knowledge about fertility preservation options [10, 12, 14, 15], lack of interprofessional networks that include fertility specialists [10, 14, 16]), and patient-related issues. In a study of pediatric oncologists, the most common reasons for not referring postpubertal boys for sperm banking were poor survival prognosis, the need for immediate initiation of treatment, and the boy's parents not providing consent [10]. In addition, other patient characteristics may influence whether fertility concerns are discussed, such as the patient's age, pubertal status, parity, marital status, and financial situation [9, 10, 14, 16]. A 2007 qualitative study of 16 oncologists found that there are both physician barriers and patient factors that inhibited discussion of fertility preservation topics [14]. Physician barriers included lack of knowledge about fertility preservation options, limited awareness of referral information for fertility specialists, the length of time the physician had been practicing (younger providers were more likely to refer patients for a fertility preservation consultation), and the physician's specialty (oncologists who administer chemotherapy are more likely than surgical oncologists to discuss fertility).

Patient factors that limited fertility preservation discussions included urgent need for cancer treatment, perception of fertility preservation as having a low priority for patients, female gender, increased parity, and greater disease stage. In a 2010 nationwide survey of 249 oncologists, more than 90% of responders believed that they were "very knowledgeable" or "aware of" fertility preservation options, yet only 17% had experience with the most established fertility preservation technique, embryo cryopreservation [12]. In addition, the study found gaps in knowledge about the risk of gonadotoxicity from specific treatment regimens. Yet the survey also indicated that perhaps oncologist awareness and knowledge about fertility preservation will improve—97% of respondents agreed with the American Society of Clinical Oncology (ASCO) guidelines about the role of oncologists in discussions of fertility with patients [17], and 75% expressed interest in attending educational seminars about fertility preservation [12]. On the other hand, while patient characteristics are not modifiable, there is no consensus about who is an "appropriate" patient for a fertility preservation consultation. Ideally, fertility concerns would be discussed with *all patients* (i.e., regardless of age, parity, or disease characteristics), and overall communication about fertility preservation will advance to allow for improved patient satisfaction.

Patients Are Not Satisfied with Fertility Preservation Communication

In general, patients are not satisfied with fertility preservation communication. Surveys of breast cancer survivors indicate that over 25–50% felt that they did not receive adequate or appropriate education, counseling, or resources about reproductive decisions prior to their cancer treatments [2, 18, 19]. In an online survey (n=228), only 11% of women with breast cancer believed that they received sufficient information about fertility preservation [18]. Survivors 25–45 years of age were asked to report if they felt that they possessed “a lot” of knowledge about factors that influence fertility. Approximately half of respondents perceived that they had a solid base of knowledge about the female reproductive cycle and general factors that affect fertility (including chemotherapy); however, fewer than 15% of subjects believed that they knew “a lot” about infertility treatments and resources. In a study by Thewes et al. in Australia, despite the fact that 71% of subjects reported having discussions of fertility-related issues with a health professional, over half of responders (breast cancer patients) felt that their most common fertility questions were *not* answered in a satisfactory way (Table 11.2) [3]. Almost 30% of those responders specifically met with a reproductive specialist, indicating that the current model of fertility preservation education may not be adequate.

Quantitative Evidence that Patients’ Fertility Preservation Needs Are Not Being Met

Recent studies have focused on objective measures of fertility preservation knowledge *before* the fertility preservation consultation, showing overall poor knowledge among patients prior to this visit [20, 21]. Higher previsit knowledge was noted in women with higher education and those who had actively sought out information prior to the consultation. Because cancer treatment usually begins soon after diagnosis, patients have a very narrow window of time to comprehend the complex issues and decisions associated with fertility preservation procedures. The language used during a fertility preservation consultation can be very specialized, involving complex medical, embryological, and statistical concepts. Compared with infertile patients who, in many cases, have been attempting pregnancy for years and are likely familiar with basic concepts at the initial visit, patients newly diagnosed with cancer must assimilate information and make decisions about undergoing fertility preservation procedure quickly. Ideally, cancer patients would present for their fertility preservation appointment with some foundation of knowledge on which to build during the consultation.

Yet, even *after* a fertility preservation consultation, objective measures of patient knowledge are poor. The average score on a validated fertility preservation knowledge scale was about 50% correct (Table 11.3) [22]. Poor comprehension of fertility preservation-related information may influence patients' ultimate decisions about participating in some form of fertility preservation procedure. In addition, patients' knowledge about the risks associated with fertility preservation procedures and the likelihood of future pregnancy after cancer is limited. Knowledge items that specifically addressed patient comprehension about risks (Q6, Q9) were answered incorrectly by approximately 50% of patients (Table 11.3). Patients' misperceptions about increased risks associated with either fertility preservation procedures or birth defects in a future pregnancy may negatively impact not only their capacity to make informed decisions about fertility preservation but also their ultimate decision about pursuing future pregnancy at all.

Table 11.3 Cancer patient knowledge of fertility preservation following the initial consultation with a reproductive specialist [22]

Validated fertility preservation (FP) knowledge tool		
Question	Correct answer	Item difficulty (% correct)
Q1. A doctor can accurately predict the effect that cancer treatment will have on someone's chance of becoming pregnant in the future	False	86.2
Q2. IVF with embryo freezing is an established treatment used for people with infertility	True	82.4
Q3. Frozen embryos have more than a 90% chance of resulting in pregnancy in the future	False	64.7
Q4. Ovarian tissue cryopreservation is a FP specific treatment	Yes	60.7
Q5. Egg freezing has the same chance of future pregnancy as embryo freezing	False	56.8
Q6. Chemotherapy increases the risk that future children will have birth defects	False	52.9
Q7. Egg freezing can be done in less than 1 week	False	52.9
Q8. Embryo freezing requires ovarian stimulation	True	50.9
Q9. Women who have fertility treatments before cancer treatment are at increased risk for recurrence of their cancer in the future	False	47.1
Q10. Frozen eggs have more than a 50% chance of resulting in pregnancy in the future	False	47.1
Q11. More than 100 babies have been born to women who had ovarian tissue freezing	False	25.5
Q12. A patient who experiences ovarian failure after cancer treatment can become pregnant in the future	True	25.4
Q13. A patient who has had an ovary removed is less likely to become pregnant in the future	False	23.5

Decisional Conflict

Many patients have significant decisional conflict about undergoing fertility preservation procedures such as embryo/oocyte cryopreservation or ovarian tissue cryopreservation. More than 60% of women express high decisional conflict regarding fertility interventions *before* their consultation with the reproductive specialist [21]. Interestingly, women with higher knowledge about fertility preservation had lower decisional conflict [21]. When asked 3–12 months *after* a consultation about fertility preservation, almost 40% of women recall a significant amount of conflict regarding their fertility preservation decision [23]. Several factors independently predict increased decisional conflict, such as older age, fewer social support systems, perceived time pressure about fertility preservation decisions, and not receiving fertility preservation treatments (such as egg or embryo banking).

How Can We Improve Communication and Facilitate Better Decision-Making?

ASCO Guidelines About Fertility Preservation in Cancer Patients

The American Society of Clinical Oncology convened a multidisciplinary panel that drafted and issued guidelines in 2006 [17]. These guidelines state “as part of education and informed consent before cancer therapy, oncologists should address the possibility of infertility... and be prepared to discuss possible fertility preservation options or refer appropriate and interested patients to fertility specialists.” While clinical judgment should be employed in the timing of raising this issue, having the discussion at the earliest possible opportunity is encouraged. Other professional societies and organizations, such as the American Society of Reproductive Medicine, the American Academy of Pediatrics, Fertile Hope, and the Oncofertility Consortium, have developed “best-practice” guidelines and educational resources designed for patients and providers [24–29].

Improving providers’ awareness of these guidelines should be a top priority to help improve patient awareness of fertility concerns and facilitate referral of interested patients to a fertility preservation specialist. Specifically, patient care will likely be improved if *earlier* referral to a reproductive specialist is implemented [30]. Breast cancer patients who were referred prior to (rather than after) surgery are more likely to have an earlier start to an ovarian stimulation cycle, an earlier start to chemotherapy, and the option for a second stimulation cycle (if desired) [30].

These provider-focused guidelines and educational tools include flow diagrams and identify “points of discussion” between the oncology team and the patient. At a minimum, two essential points that the oncology team must communicate successfully with all reproductive-age cancer patients are:

- Cancer treatments may cause future fertility problems.
- Patients who express any interest in his/her future reproductive options can be referred to a reproductive specialist and/or a psychosocial counselor.

Table 11.4 Points of discussion regarding fertility preservation between the patient and the oncology professional from the ASCO guidelines [17]

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- Cancer and cancer treatments vary in their likelihood of causing infertility
 - Individual factors such as disease, age, treatment type and dosages, and pretreatment fertility should be considered in counseling patients about the likelihood of infertility
 - Patients who are interested in fertility preservation should consider their options as soon as possible to maximize the likelihood of success
 - Some female treatments are dependent upon the phase of the menstrual cycle and can only be initiated at monthly intervals
 - Discussion with fertility specialists and review of available information from patient advocacy resources can facilitate decision-making and treatment planning
 - The two methods of fertility preservation with the highest likelihood of success are sperm cryopreservation for males and embryo freezing for females
 - Conservative surgical approaches and transposition of ovaries or gonadal shielding prior to radiation therapy may also preserve fertility in selected cancers
 - All other approaches are considered experimental
 - Data are very limited, but there appears to be no detectable increased risk of disease recurrence associated with most fertility preservation methods and pregnancy, even in hormonally sensitive tumors
 - Aside from hereditary genetic syndromes and in utero exposure to chemotherapy, there is no evidence that a history of cancer, cancer therapy, or fertility interventions increase the risk of cancer or congenital abnormalities in the progeny
 - Treatment-related infertility may be associated with psychosocial distress, and early referral for counseling may be beneficial in moderately distressed people
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These two points can be broached by nonphysician members of the oncology team (such as nurses, social workers, therapists). The reproductive specialist should also provide a comprehensive consultation to interested patients, detailing risks of their cancer or cancer treatment to fertility (see Chaps. 1 and 2 in this volume), pregnancy after cancer (see Chap. 10 in this volume), and all appropriate fertility preservation treatment options (see Chaps. 3, 4, 5, and 6 in this volume). If members of the oncology team feel comfortable discussing fertility in more detail, the ASCO guidelines provide additional “talking points” (Table 11.4) [17]. These points may be discussed early after diagnosis, as patients decide about whether to pursue a fertility preservation consultation, or later in the process, if patients request their oncologist’s opinion regarding their fertility preservation options.

Patients Can Seek Information Themselves

If the oncology team does not broach the topic of fertility and cancer, ideally, patients should mention their concerns as early as possible when discussing cancer treatments. Organizations such as Fertile Hope and the Oncofertility Consortium have patient-friendly websites, handouts, hotlines, and even smartphone applications to facilitate patient awareness and provide educational support ([27, 29]; also see Chap. 12 in this volume). Myoncofertility.org has a list of suggested questions for patients to ask members of their oncology team (Table 11.5).

Table 11.5 Five fertility questions that cancer patients could ask their providers (Source: <http://myoncofertility.org>)

How is my cancer affecting my health right now?
How quickly do I need to start treatment?
Will my cancer or its treatment affect my future fertility?
What fertility preservation options are out there?
Can I have a child after my cancer?

Can We Improve Educational Methods About Fertility Preservation?

Ideally, we can improve the fertility preservation process in ways that will decrease decisional conflict, improve patient satisfaction, and allow patients to make high-quality, informed decisions. A first step is to try to improve comprehension about fertility preservation. It has been shown that knowledge and understanding of disease and treatment are closely linked to patient outcomes and quality of life [31]. Potentially, education about fertility preservation could begin at the time that the oncologist offers their patient a referral to a reproductive specialist. Patient knowledge about fertility preservation prior to their consultation with the reproductive specialist is currently very limited, which means that patients have to process a great deal of complex medical information during their initial meeting with the fertility preservation specialist. Not surprisingly, patients who had sought out websites such as *fertilehope.org* prior to their fertility preservation consultation had improved pre-visit knowledge [32]. One possible approach to improving cancer patients' understanding of fertility preservation issues is for the oncologist to direct patients to educational resources that should be utilized prior to the consultation with the reproductive specialist; these resources would introduce general ideas and vocabulary about reproduction and fertility that would prepare them to comprehend and participate in a discussion of the complex concepts and issues of fertility preservation with the reproductive specialist.

In addition, there is evidence that the current model of a single fertility preservation consultation between cancer diagnosis and cancer treatment does not allow the majority of patients to comprehend significant amounts of fertility preservation information. One study investigated potential factors that are associated with higher post-consultation fertility preservation knowledge scores [21]:

- Additional contact with the fertility specialist—perhaps, a second contact between the patient and the reproductive specialist should be standard of care, whether it is a phone call or a second office visit.
- Discussing fertility preservation options with someone else after the fertility preservation consult.
- Patients who used specific websites such as *fertilehope.org* and *myoncofertility.org* as opposed to general Internet searches—patients should be encouraged to explore specific dedicated fertility preservation educational resources. For women who are unable to undergo a full fertility preservation consultation

(due to geographical, financial, or time constraints), referral to educational websites is especially crucial.

- College education—while this is not modifiable, fertility specialists may need to modify their fertility preservation consultation based on education level to improve patient comprehension of complex fertility preservation information. Perhaps having patients complete a “knowledge survey” (Table 11.3) *prior* to their fertility preservation consultation will help providers tailor their language and educational message for individual patients’ needs.

Patients state that their preferred method to receive information about fertility-related issues is through an individual consultation with a fertility specialist [3]. This was followed by a decision aid, an informational video, and a question prompt sheet, though these tools have yet to be developed for a fertility preservation application. In the future, new technologies may allow for interactive tools that not only reinforce fertility preservation information but assist patients in decision-making.

Looking Forward

There is evidence that communication with patients may be improving and providers are more successfully educating patients about the risks posed by their cancer or its treatment to future fertility. In the study by Partridge et al., women diagnosed with breast cancer recently were more likely to know about the impact of chemotherapy on fertility compared with women who were diagnosed several years ago ($P=0.003$). However, unresolved ethical and practical issues exist (see also Chap. 9 in this volume):

- What is the role of fertility preservation in patients with an extremely poor prognosis?
- How can we address the all-too-frequent problem of financially constrained patients who cannot afford the high costs of assisted reproductive technologies, especially when insurance rarely covers fertility preservation treatments? If the costs are likely to be a major constraint for individual patients, they may not know this limitation up front and plan for fertility preservation treatments only to discover later that this is not feasible for them.
- How can we provide fertility preservation information and treatments to patients who live in regions that do not have ready access to fertility specialists?
- How should we address the frequently divergent opinions of parents and children about fertility preservation options?
- How can we provide rapid, easily accessible fertility preservation information to patients with cancer, who may not be in the “right frame of mind” to absorb this complex information and make informed decisions?

In the future, perhaps novel approaches will improve patient communication about fertility preservation, especially in the challenging setting of a recent cancer diagnosis. For example, web-based interactive educational tools and decision aids

may provide improved access to fertility preservation information and allow for higher decisional satisfaction for reproductive-age cancer patients. In addition, continuing to strive for universal discussions about fertility concerns for all patients will help avoid current biases in referral patterns based on patient characteristics like parity and prognosis. Multidisciplinary clinics have become more common in disciplines such as breast cancer, where surgeons, genetics counselors, medical oncologists, and others come together to provide comprehensive care. Fertility preservation should be included in this multidisciplinary approach to patient care.

More research is needed to address these dilemmas in patient-provider communication, and it is hoped that in the near future, appropriate and thorough discussions about the risks to future fertility will be part of routine counseling for all reproductive-age cancer patients.

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