

## Chapter 10

# Fertility Communication to Cancer Patients: A Hematologist–Oncologist’s Perspective

Sara Barnato Giordano

As cancer treatments continue to advance, ~80 % of adolescents and young adults who receive a cancer diagnosis become long-term survivors. The increased survival has resulted in a focus in the long-term effects of therapy and a patient’s quality of life. Oncologists must identify and address important quality of life issues that affect the well being of their patients. It is important both during treatment planning and in survivorship follow-up. Many studies have shown that young women with cancer have concerns related to sexual health, treatment-induced infertility, and menopause [1–3]. There is substantial room for improvement in communication and counseling of sexual health concerns, as well as the ability to provide resources and information for those women who demonstrate interest in fertility preservation.

Cancer treatments, including chemotherapy, radiation or surgical treatment may result in sexual dysfunction, cause menopausal symptoms, and/or impair fertility. Frequent complaints include loss of libido, vaginal dryness, dyspareunia, and decreased personal and partner satisfaction [4, 5]. Young women who experience amenorrhea as a result of their cancer treatment are likely to experience menopausal symptoms, including hot flashes, insomnia, and fatigue. Chemotherapy and radiation therapy may reduce the number of viable ovarian follicles in a drug- and dose-dependent manner, and surgical treatment may induce changes in a female’s anatomy which can interfere with their ability to conceive after therapy is complete. Awareness and counseling by the physician is an integral part of patient care that is often overlooked or not discussed in premenopausal women with cancer.

The American Society of Clinical Oncology (ASCO) has recognized the need for improvement in counseling these women and for proper referrals to reproductive health care specialists. In 2006, ASCO published guidelines which suggested that oncologists “should address the possibility of infertility with patients treated during

---

S.B. Giordano, M.D. (✉)

Assistant Professor, Division of Hematology and Oncology, Medical University of South Carolina, 173 Ashley Avenue, BSB104, MSC 635, Charleston, SC 29425, USA  
e-mail: sbarnato@gmail.com

their reproductive years and be prepared to discuss possible fertility preservation options or refer appropriate and interested patients to a reproductive specialist” [6].

ASCO subsequently added two practice quality measures on fertility preservation to the Quality Oncology Practice Initiative (QOPI) program in 2007 to reflect the ASCO guidelines [7]. The QOPI program established age-based parameters to provide guidance on choosing appropriate patients for fertility discussions. Currently, conditions such as disease stage, disease prognosis, and curability do not exclude patients from the recommendations.

A survey conducted and published by Quinn and colleagues after the ASCO guidelines were created, demonstrated that less than half of oncologists are following these recommendations and that 25 % of oncologist reported routinely referring patients for fertility preservation, and only 38 % reported knowledge of the QOPI guidelines. Their reasons for lack of discussion or referral had to do with the lack of the oncologist’s knowledge about referrals, their perception that patients could not delay treatment, and their perception that patients were not interested in discussing fertility preservation because it was not mentioned by the patient [8]. Data from the QOPI program also confirm many oncologists are not discussing infertility risk involved with chemotherapy and fertility preservation options. More research is needed to focus on the many barriers to the oncologist’s ability to provide such discussions and resources and for the development of interventions to overcome such barriers.

## **Barriers to Fertility Preservation**

With the release of ASCO guidelines in 2006, the role of the oncologist in discussing potential infertility due to cancer treatments and fertility preservation options has been delineated. Despite these guidelines, rates of discussion and referrals have been suboptimal. Several studies have identified significant barriers to this important communications process. Barriers exist within the health care system, by the physician, between the physician and patient, and by the patient.

### ***Health Care System Barriers***

While national guidelines exist regarding fertility discussion or referrals for fertility preservation, many hospital policies and practices do not correspond with the guidelines. The dissemination of guideline information is not instantaneous with physicians and nurses often unaware of practice guidelines. Even when parties are aware of the guidelines, there can be communication gaps within the health care system. Within an institution it is important to delegate which provider, the physician, pharmacist, mid-level, or nurse, will cover the discussion on the potential for infertility with the patient. In addition, it is critical for the provider to be aware of

available sperm banks, reproductive urologists, and reproductive endocrinologists available at the institution or city [9].

Health insurance often poses a barrier to reproductive assisted technologies as insurance coverage is rarely available. The potential costs involved in most procedures are not only prohibitive for many cancer patients, but they also serve as a barrier for health care professionals to discuss these expensive options. No single state mandates coverage for fertility preservation for cancer patients prior to treatment. In addition, the legal definition of infertility does not apply to cancer patients who need fertility procedures in a timely manner. Infertility is defined as an inability to conceive despite attempts to become pregnant through unprotected intercourse for at least 1 year. For cancer patients who need to bank sperm or stimulate their ovaries for egg and/or embryo banking prior to their cancer therapy, they do not meet the state definition of infertility and may have difficulty obtaining reimbursement for the fertility preservation procedure [10]. LIVESTRONG's Sharing Hope program provides financial assistance to eligible patients undertaking fertility preservation at participating centers [9]. Access to the Sharing Hope program and the proposal of new health policies ultimately leading to insurance coverage can aide in solving one of the many issues young cancer patients face.

### *Physician Barriers*

Even with national guideline recommendations in place, many physicians are reluctant to endorse fertility preservation. Studies looking at this specific topic have found physicians' knowledge about fertility and attitudes about discussing risks and preservation options as key barriers, as patients are strongly influenced by the messages they receive from their health care provider. A key obstacle is the concern among many oncologists that discussing the risk of infertility and fertility preservation is neither appropriate nor an immediate clinical priority. Also physicians often have perceptions that financial costs of fertility preservation may be too high for certain families. A study by Vadapampil et al. considered barriers to fertility preservation among pediatric oncologists [11]. Interviews were conducted with pediatric hematologists/oncologists practicing in Florida. Responses were characterized by primary healthcare barriers, physician perceptions of desire for information, patient characteristics that may impact fertility preservation discussions, and issues unique to adolescent patients. Physician factors were related to lack of formal training in fertility preservation and lack of adequate referral information about fertility preservation. What was also noted in the survey was that the majority of pediatric oncologists expressed a desire for fertility preservation institutional guidelines.

A study by Kohler and colleagues surveyed pediatric oncologists' attitudes towards fertility preservation [12]. Results from the study suggest that while pediatric oncologists acknowledge the importance of addressing fertility preservation, less than half reported they refer male patients and only 12 % reported they refer female patients to a fertility specialist prior to treatment. In regard to the ASCO guidelines, 44 % noted they were familiar with them.

These studies are just a few of the many examples that demonstrate many providers often lack knowledge about fertility preservation, have the perception that the subject of fertility preservation adds more stress to the situation, and have general uncertainty about success of fertility preservation methods. In addition, many are unaware of current guidelines. Improved methods for information transmission are needed. Regardless of the uncertainty, there is general agreement that reproductive and sexual health of young cancer patients is important and the implementation of institutional guidelines for introducing, discussing, and providing fertility preservation services is warranted.

### *Communication Barriers*

During a new patient consultation, patients are often flooded with new information regarding their diagnosis, therapeutic options, clinical trial availability, review of therapy-related toxicities, and discussion on prognosis. Each one of these issues requires attentive and delicate communication in a time efficient manner. With such patients, the delayed side effects of therapy, including infertility risk and fertility preservation are equally challenging and often times may seem inappropriate to both the physician and the patient. Some patient's feel discussing fertility at the time of diagnosis is futile as their focus is on saving their own life, vs. creating a new one. However multiple studies show patients experience regret once the shock of the initial diagnosis has lessened or once treatment is underway or complete [13].

Faulty timing of fertility preservation discussions and the way the information is provided to the patient is also a barrier to pursuing fertility preservation. The window is usually narrow for a woman to seek consultation for fertility preservation options and to undergo ovarian stimulation. Therefore the discussion is required during the initial hematology or oncology consultation. In addition, the delay in treatment initiation can also become a barrier. Some malignancies require immediate treatment, at which point fertility preservation should not be considered. Even so, the potential risk should still be discussed with the patient. The oncologist may also be concerned that a patient's choice to pursue fertility preservation could delay chemotherapy, possibly compromising treatment outcomes and impeding the delivery of quality care. Studies looking at factors affecting decision-making about fertility preservation uniformly conclude with the suggested need for an early appointment with a fertility expert [14]. It is critical that the oncologist discuss these issues with the patient and not make a choice for the patient without the patient's consent.

Multiple studies and discussions with survivors suggest patients do not recall having a fertility preservation conversation with their doctor. What is not known is if these discussions did occur and were not remembered or if these conversations did not take place at all. What is known, however, is that the ability to have biological children in the future is extremely important to the vast majority of cancer patients. Feelings of decreased self-esteem, body image, and concern regarding intimate relationships are frequent among these patients. And even if having additional

children may not be possible for a patient with incurable cancer, it is important for the patient to be aware of the risk and to be able to make the choice to pursue or forego fertility preservation independently on the basis of information provided by the oncologist.

### ***Adolescent and Young Adult Barriers***

Both males and females may experience emotional as well as physical barriers to using fertility preservation. Communication about sperm storage and ovarian stimulation may be uncomfortable for the young adult patient. In some cases, young men may be unprepared for the physical process of sperm banking and may need support from a team of experts. Also, the process of preservation is more complicated for women. Embryo and egg banking are both nonexperimental techniques for fertility preservation, however each with their own challenges. Egg cryopreservation is a less tested method, and depending on an institution's expertise, may not be an option for all female patients. Embryo cryopreservation poses a challenge if females do not have a sperm donor or if they are uneasy about using a sperm bank.

### ***Parent Barriers***

Parental communication barriers surrounding their teenager or young adult cancer diagnosis include lack of knowledge about emotional development and cognitive processes of the adolescent/young adult, and varying religious or culture values. Parents can lack information regarding the details about the cancer diagnosis, treatment plan, and side effects, all of which may provide an additional barrier to fertility preservation. There are times when the patient and the parents concerns are at odds. This is an area in which many physicians lack the training to effectively communicate with both parties.

### **Fertility Preservation in the Incurable Patient**

On the basis of the ASCO guidelines [6], one of the QOPI measures assesses whether oncologists discuss infertility risk with their patients before they begin anticancer therapy. Discussing infertility risk and fertility preservation with patients not being treated with curative intent may be uncomfortable, and the topic should be handled carefully and sensitively. It is important for the oncologist to not withhold information from the patient regarding potential fertility loss and to assess each patient's wishes and concerns and facilitate access to information as needed. One suggestion is that after discussing the diagnosis with the patient and informing

the cancer is not curable, the physician can acknowledge that often patients in similar situations still wonder about having children. At that point, recognizing the news is upsetting and referral to a fertility specialist should be offered.

## Conclusion

Concerns about future fertility are common among patients with cancer and have a significant impact on quality of life. Ultimately the responsibility for conveying information about fertility and childbearing in relation to the cancer diagnosis and treatment lies in the hands of the medical professionals, specifically the treating oncologist. The ASCO guidelines recommend oncologists address these concerns with patients and their families. The QOPI measures are a useful mechanism for quality improvement efforts and assess whether discussion and referrals take. Also, stimulating greater communication and referral patterns between hematologist–oncologists and specialists in reproductive medicine will help ensure these patients are able to receive the specialty care they need. And with greater publicity surrounding this topic, patients and their families can become their own advocate and request information and services for fertility preservation and testing if their physician does not offer it.

Issues of fertility and reproduction are important to most patients with cancer of reproductive age. New methods of communication between all parties, physicians, patients, and parents, must be examined. Healthcare providers need training and guidelines on how to discuss fertility-related issues and concerns. Also, the ASCO guidelines and QOPI quality assessment measures regarding communication about infertility and fertility preservation options are appropriate additions to the overall effort to improve quality of care.

**Acknowledgments** This work was supported by the Oncofertility Consortium NIH 5UL1DE019587 and TL1CA133837.

## References

1. Partridge AH, Gelber S, et al. Web-based survey of fertility issues in young women with breast cancer. *J Clin Oncol*. 2004;22(20):4174–83.
2. Thewes B, Meiser B, et al. Fertility- and menopause-related information needs of younger women with a diagnosis of early breast cancer. *J Clin Oncol*. 2005;23(22):5155–65.
3. Nakayama K, Liu P, et al. Receiving information on fertility and menopause related treatment effects among women who undergo HSCT: changes in perceived importance over time. *Biol Blood Marrow Transplant*. 2009;11:1465–74.
4. Dizon D. Quality of life after breast cancer: survivorship and sexuality. *Breast J*. 2009; 15(5):500–4.
5. Schover LR. Premature ovarian failure and its consequences: vasomotor symptoms, sexuality, and fertility. *J Clin Oncol*. 2008;26:753–8.

6. Lee S, Schover LR, et al. American Society of Clinical Oncology recommendations on fertility preservation in cancer patients. *J Clin Oncol*. 2006;24(18):2917–31.
7. American Society of Clinical Oncology: QOPI Methodology. <http://qopi.asco.org/Methodology>
8. Quinn GP, Vadaparampil ST, et al. Physician referral for fertility preservation in oncology patients: a national study of practice behaviors. *J Clin Oncol*. 2009;27(35):5952–7.
9. Kelvin JF, Reinecke J. Institutional approaches to implementing fertility preservation for cancer patients. *Adv Exp Med Biol*. 2012;732:165–73.
10. Knapp CA, Quinn GP, et al. Patient provider communication and reproductive health. *Adv Exp Med Biol*. 2012;732:175–85.
11. Quinn GP, Vadaparampil ST. Fertility preservation and adolescent young adult cancer patients: physician communication challenges. *J Adolesc Health*. 2009;44(4):394–400.
12. Kohler TS, Kondapalli LA, et al. Results from the survey for preservation of adolescent reproduction (SPARE) study: gender disparity in delivery of fertility preservation message to adolescents with cancer. *J Assist Reprod Genet*. 2011;28(3):269–77.
13. Crawshaw MA, Glaser AW, et al. Male and female experiences of having fertility matters raised alongside a cancer diagnosis during the teenage and young adult years. *Eur J Cancer Care*. 2009;18(4):381–90.
14. Peddie VL, Porter MA, et al. Factors affecting decision making about fertility preservation after cancer diagnosis: a qualitative study. *BJOG*. 2012;119:1049–57.