Chapter 7
Genetic Counselors: Bridging the Oncofertility Information Gap

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Introduction

Approximately 1,660,290 new cancer cases will be diagnosed in 2013, 805,500 of which will be in women [1]. Approximately 10 % of those cancer diagnoses will occur in individuals younger than 45 years, and thus still within their reproductive years [2]. Additionally, the 5-year relative survival rate for all cancers diagnosed between 2002 and 2008 is 68 %, up from 49 % between 1975 and 1977 [1]. The increase in survival rate can be attributed to progress in earlier diagnosis and improvements in treatment. With an increase in cancer survival, we can expect that more young women diagnosed with cancer will be seeking information about fertility preservation prior to cancer treatment. In fact, approximately 75 % of young adult cancer survivors who have not previously had children express a desire for children in the future [2].

The goal of oncofertility is to balance life-preserving cancer treatments with fertility preserving options. Three main gaps have created an unmet need for preserving fertility in patients with cancer: an information gap, a data gap, and an option gap. The information gap, in particular, involves a lack of cancer patient understanding regarding the effects of cancer treatment on fertility and the option of fertility preservation. Many cancer patients do not recall ever discussing the impact of cancer treatment on fertility with their physician; because of this,

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T.K. Woodruff et al. (eds.), *Oncofertility Communication: Sharing Information and Building Relationships across Disciplines*, DOI 10.1007/978-1-4614-8235-2_7,

multidisciplinary care that includes fertility treatment is especially valuable for bridging the information gap. In particular, genetic counselors, who are specifically trained to deliver options and facilitate decision making while also focusing on psychosocial issues, are an untapped resource for educating cancer patients about fertility impairment and fertility preservation options. Genetic counselors have the skills necessary to bridge the oncofertility information gap.

The Oncofertility Information Gap

Advances in cancer diagnostics and treatments have redefined the previous treatment-based approach to a broader perspective including survivorship and quality of life [3]. This new longer-term perspective on cancer care has revealed gaps in clinician–patient education, communication, and decision support with regard to fertility preservation that need to be addressed.

Lack of Oncofertility Patient Education and Communication

As part of their care, oncology healthcare providers should not only focus on the short-term goal of treatment and survival but also help cancer patients to preserve the best possible quality of life, including the possibility of having children [4]. If women are not informed of the risk that cancer treatment poses to their fertility, they may lose the opportunity to preserve their fertility prior to cancer treatment [5]. Even women who choose not to become parents value the opportunity to preserve their fertility [6]. Fertility preservation is especially important in adolescent and young adult patients with cancer, and unfortunately it is one of the most underprescribed and least implemented services in their cancer care [7]. The National Comprehensive Cancer Network (NCCN) guidelines for young adults with cancer state that fertility preservation should be an essential part of cancer management, and the risk of infertility associated with cancer therapy should be discussed at the time of diagnosis [7]. Yet, up to 75 % of young women express interest in the opportunity to have children after a cancer diagnosis, but as few as 34 % of reproductive-age women treated for cancer recall having a discussion about the effects of cancer treatment on fertility [5]. The lack of patient education about fertility preservation is associated with the desire of the healthcare provider to start cancer treatment immediately, a lack of adequate knowledge regarding fertility preservation by the cancer care team, and insufficient provider–patient communication skills.

Many oncologists leave little time to discuss future fertility or options for fertility preservation with their patients because the immediate focus is on cancer treatment [8]. In their recent survey of women with cancer and healthcare professionals involved in cancer care, Peddie et al. reported that few women were afforded the opportunity to discuss the benefits and limitations of fertility preservation options available to them [8]. The clinical staff felt justified in withholding fertility information from women and guiding their decision making because of their belief that treatment was urgently needed, fertility preservation techniques were not effective or useful, or that fertility would not be affected by first-line chemotherapy.

In addition to their focus on the immediate need to start treatment, healthcare providers may not have adequate knowledge or sufficient communication skills to counsel concerned patients in a timely and supportive manner [9]. Physicians rarely ask about patients' concerns and questions in the oncology setting [10]. Some oncologists cite that lack of discussion is due to the perception that if a patient did not raise the issue themselves, then they were not interested [5].

Patient communication involves not only the transfer of information but also the provision of psychological and emotional support. Emotional support for young women with cancer is especially important because they experience greater distress and less emotional well-being than older women [3]. Without proper training in patient counseling, however, oncology providers may find it challenging to offer psychological and emotional support to their patients. Counseling requires the ability to take into account a patient's individual background, provide information and support in a timely and accurate manner, and address the patient's emotional needs [9]. In a recent study by Kirkman et al., young women with cancer reported that their psychosocial needs were not met and staff numbers in psychology and counseling were inadequate [6]. In another study, women cancer survivors reported that fertility was a vital concern because they wanted to preserve not only quality of life after cancer but also protect their mental and emotional health [4]. Patients also report wanting healthcare providers who are honest, compassionate, and patient [11]. We believe that healthcare providers with proper training in counseling are better equipped to provide emotional support to cancer patients and therefore facilitate discussions of fertility preservation and post-cancer quality of life.

To address psychosocial and behavioral issues, the NCCN provides a detailed list of support healthcare workers who can provide counseling to young adults with cancer. These patients need healthcare providers who are able to assess cognitive function, emotional issues, and evaluate other psychiatric symptoms, depression, and anxiety. Additionally, healthcare providers offering psychosocial support to young adult cancer patients need to be able to take into consideration patient existential/spiritual issues, personal relationships, decision-making preferences, and communication preferences that may affect cancer treatment and fertility preservation decisions [7].

Lack of Oncofertility Patient Decision Support

A lack of support for patient decision making also contributes to the oncofertility information gap. Patients value fertility preservation and those healthcare providers who recognize that child bearing is a future option [6]. Patients want healthcare providers to offer options—including a discussion of the off-target effects of cancer treatment—and to support the decision to try for pregnancy after cancer treatment [6]. Patients can be particularly troubled when their fertility concerns are not well managed. In the Kirkman et al. study, some women reported feeling excluded from discussions and decision making about their own fertility [6]. They were given minimal information and regret not being treated with consideration, especially when unwarranted assumptions were made about their fertility plans.

Healthcare providers should not assume that they understand patient fears, priorities, or preferences related to their cancer treatment and fertility preservation. Doing so may influence the quality of the information a provider gives to a patient [8]. Alternatively, healthcare providers should be supportive of patient decisions and implement the use of the shared decision-making model, discussed in more detail below.

Multidisciplinary Care

The oncofertility information gap can be addressed with multidisciplinary care. Kirkman et al. identified this team approach to cancer care as especially valuable in their qualitative study of the significance of fertility and motherhood after a cancer diagnosis [6]. Multidisciplinary team members should be experienced in cancer care as well as sensitive to fertility concerns. Cancer patients report a desire for referral to fertility specialists, psychological support, and counseling, emphasizing the importance of a multidisciplinary approach to cancer care that includes fertility preservation [6].

Multidisciplinary care also mitigates the need for the integration of the sensitive topic of fertility into an already overwhelming oncology consultation. Patients are given a lot of information at their first oncology visit and are also at their most vulnerable [8]. A discussion of fertility and fertility preservation may not be beneficial or realistic immediately after a cancer diagnosis. Research suggests that recruiting the help of healthcare workers who have special training to address fertility issues in the confusing period of time just after a cancer diagnosis can be helpful [12].

The Role of the Genetic Counselor

Genetic counselors are medical professionals who have undergone extensive graduate level human genetics and psychosocial coursework. They possess the necessary skill sets to deliver options and facilitate decision making while also focusing on psychosocial issues. The four critical domains that genetic counselors demonstrate competency in are communication, critical thinking, psychosocial assessment, and professional ethics and values [13]. A typical genetic counseling session for a patient with cancer may involve the following components: pedigree analysis, risk assessment, genetic testing options, genetic testing results interpretation, facilitation of medical management decision making, and discussion of risk for family members.

Genetic counseling practice is guided by the ethical principle of nondirectiveness [14]. A nondirective counseling approach allows genetic counselors to support client autonomy and facilitate informed patient decision making [15]. Additionally, psychosocial training gives genetic counselors the necessary skill set to provide emotional support to patients as well as make mental health referrals when needed. Genetic counselors who work in cancer clinics are in the unique position of being able to utilize their skill sets to discuss fertility preservation options with patients in that sensitive window of time prior to cancer treatment or prophylactic surgery.

Nondirectiveness

The guiding ethical principle of genetic counseling—nondirectiveness—is an active counseling strategy used by genetic counselors to promote patient autonomy. The goal of this approach is to increase patient self-esteem and enable patients to make independent, informed decisions free from coercion [16]. Nondirective counseling techniques employed by genetic counselors leave patients with greater sense of control over their lives and decisions [14]. The nondirective approach used by genetic counselors differs from the typical healthcare provider content-oriented approach. Nondirectiveness is person-oriented, meaning that it places emphasis on what facts and information mean to a patient as well as the intrapsychic and interpersonal consequences of these meanings [16]. In order to implement a nondirective counseling approach, genetic counselors begin by identifying their own personal biases and intentions [16]. This is done in order to direct the process of genetic counseling but not direct the outcome.

Decision Making

Important medical decisions that affect quality of life, such as whether to pursue fertility preservation prior to cancer treatment, should follow the shared decision-making model. With this approach, healthcare providers are respectful of their patients’ perspectives and take into consideration patient values and self-efficacy. Patients should be informed of all relevant options, including the corresponding risks and benefits, in order to make informed medical decisions [17]. Genetic counselors facilitate informed medical decision making by patients for genetic testing, screening, and treatment, including chemoprevention and risk-reducing surgery. They are able to provide relevant information, reduce anxiety, and empower patients to make decisions through nondirective counseling.

Shared decision making has four key principles. The first is that two participants are involved—the patient and the healthcare provider. Genetic counselors take steps to develop a partnership with their patient. The second principle is the sharing of information. Genetic counselors first establish and review patients' preferences for receiving information and then respond to ideas, concerns, and expectations. A decision being made is the third principle. To do this, genetic counselors identify choices and evaluate available evidence, then present the evidence and help the patient reflect upon and assess the impact of alternatives in the context of their values and lifestyle. The fourth principle of the shared decision-making model is both parties agreeing to the decision. Genetic counselors use their skills to manage conflicts that arise from the decision. They also agree upon an action plan and arrange for follow up [18].

Psychosocial training allows genetic counselors to assess which phase of the decision-making process a patient is in: identify, contemplate, resolve, and engage. Once a genetic counselor has assessed the stage of the decision-making process, they can use the appropriate counseling techniques to reach the goal of a firm decision.

Psychosocial Skills

Genetic counselors undergo extensive psychosocial training that allows them to provide emotional support to cancer patients, assess patient psychosocial situations, and provide the appropriate mental health referrals. Examples of techniques genetic counselors use to gather and assess psychosocial information from patients include reflective listening, assessment of patient understanding, and empathy.

Reflective listening is a patient-centered approach that involves more listening than talking [9]. Genetic counselors respond to personal statements that patients make, rather than to impersonal, distant, or abstract thoughts. The technique of restating and clarifying what a patient has said is commonly used by genetic counselors to assess the emotional state of patients. Reflective listening allows understanding of the feelings involved in what a patient is saying, not just the facts or ideas [9].

Another technique genetic counselors use to provide psychosocial and emotional support is eliciting the patient's understanding and evaluation of the provided information [9]. Additionally, genetic counselors use acceptance and empathy when responding to patients.

Genetic counselors can reduce patient anxiety, enhance the patient's sense of control and mastery over life circumstances, increase patient understanding of the genetic disease and options for testing and disease management, and provide the individual and family with the tools required to adjust to potential outcomes [13]. The unique skill set of genetic counselors can be used to address the effects of cancer treatment on fertility as well as fertility preservation techniques for women with a personal or family history suggestive of a hereditary or familial cancer.

Genetic Counselors and Fertility Preservation

Volk et al. conducted a research study to estimate genetic counselors' attitudes, knowledge, and discussion of fertility preservation in referred breast and ovarian cancer patients, including *BRCA1* and *BRCA2* mutation-positive patients [19]. A total of 218 genetic counselors participated in the research study, citing an average of 15.5 breast or ovarian cancer patients per month and 2.4 *BRCA* mutation-positive patients per month. Of these, more than 50 % had a basic understanding of embryo cryopreservation, egg cryopreservation, ovarian tissue cryopreservation, and emergency IVF, and were aware of fertility preservation research. Several study themes emerged, including the general belief that fertility preservation discussions are important and part of the role of the genetic counselor. The study also identified barriers that prevent genetic counselors from discussing fertility preservation with their breast and ovarian cancer patients; the primary obstacle was the timing of cancer treatment.

Genetic Counseling for Breast and Ovarian Cancer

In the general population, approximately 12 % of women will develop breast cancer and 1.4 % will develop ovarian cancer in their lifetime [1]. It is estimated that 29 % of all new female cancer diagnoses in 2013 will be breast cancer and 3 % of all new female cancer diagnoses will be ovarian cancer [1]. Approximately 3–7 % of women with early-stage breast cancer are under the age of 40 at diagnosis [1], and therefore may be interested in learning how cancer treatment can affect fertility as well as fertility preservation options.

Between 5 and 10 % of breast and ovarian cancers are associated with a hereditary predisposition [20, 21]. Deleterious mutations in the *BRCA1* and *BRCA2* genes cause 80 % of hereditary breast cancer and 90 % of hereditary ovarian cancer [20]. The average age of hereditary breast or ovarian cancer diagnosis in women is lower than that in the general population. For women with the *BRCA1* mutation, the average age at diagnosis is 39.9–44.1 years for breast cancer and 49–53 years for ovarian cancer; for women with a *BRCA2* mutation, the average age of diagnosis is 42.2–47.3 years for breast cancer and 55–58 years for ovarian cancer. By comparison, in the general population, the average age of diagnosis is 61 years for breast cancer and 63 years for ovarian cancer [22].

Female *BRCA* mutation carriers have much higher lifetime risk of ovarian cancer, between 15 and 60 %, compared to the general population risk of 1–2 %. Even with current screening options—CA-125 testing and transvaginal ultrasound—ovarian cancer is difficult to detect at an early, treatable stage.

Therefore, the NCCN and the American College of Obstetricians and Gynecologists (ACOG) recommend that *BRCA* mutation-positive women consider undergoing risk-reducing prophylactic bilateral salpingo-oophorectomy (BSO) between 35 and 40 years of age, or when childbearing is complete [11, 22, 23]. Prophylactic BSO at ages younger than 35 may be recommended based on family history [11]. Greater than 80 % of women with a *BRCA* mutation who are eligible for prophylactic BSO will pursue surgery [11]. Campfield et al. found that of 98 female *BRCA* carriers, 85 % pursued PBSO after learning of their *BRCA* status and 48 % were premenopausal at the time [11]. Additionally, 70.4 % of the study participants had discussed their surgery with a genetic counselor, while another 11.8 % would have liked their healthcare providers to refer them to a genetic counselor and direct them to other resources or programs for additional information [11].

Women with *BRCA* gene mutations may have additional concerns about passing on hereditary cancer to future children [24]. Preimplantation genetic diagnosis (PGD) is one option for parents who want to prevent this possibility. Since 2006, PGD has been used in conjunction with in vitro fertilization (IVF) to screen for specific genetic or chromosomal abnormalities, including *BRCA* gene mutations [24]. Genetic counselors can discuss the possibility of PGD with women who have hereditary breast or ovarian cancer and are considering fertility preservation.

Individuals with a personal or family history suggestive of a hereditary or familial cancer should be referred for further counseling and risk assessment [25], whether to genetic counselors or other healthcare professionals who are trained to do so. For patients who have a personal or family history suggestive of a hereditary or familial cancer, a genetic counseling session to discuss breast and ovarian cancer treatment, *BRCA1*/*BRCA2* mutation testing, and prophylactic surgery provides an opportune time to discuss the effect of cancer treatment on fertility and fertility preservation options.

Genetic Counselor Attitudes Towards Fertility Preservation

Almost all (98.7 %) of the participating genetic counselors in the Volk et al. study agreed or strongly agreed that breast and ovarian cancer patients should be told of the risk to fertility associated with cancer treatments [19]. In addition, the majority (95.4 %) agreed that patients should be offered a fertility preservation referral prior to cancer treatment, and (85.9 %) agreed if one was not offered prior to treatment, a referral should be offered after cancer treatment. Approximately 70.2 % of genetic counselors believed that discussing fertility preservation with their breast and ovarian cancer patients is part of their role as genetic counselors. A majority (61 % and 65.4 %, respectively) also stated that both cancer and *BRCA* mutation-positive patients have asked about the potential threats to their fertility caused by treatment. In fact, most genetic counselors stated that fertility options were a major concern for all of their cancer patients (51.7 %) as well as *BRCA* mutation-positive patients (63.8 %).

Fertility preservation was a major concern for those *BRCA* mutation-positive patients who were considering prophylactic BSO; 85.5 % of genetic counselors agreed that *BRCA* mutation-positive patients should be offered a fertility referral prior to undergoing this procedure, and 71.1 % reported that they have had patients inquire about the associated fertility complications of BSO.

The majority of genetic counselors in the study stated that cancer patients have asked about fertility problems associated with both surgical and nonsurgical treatment options, *BRCA* mutation-positive patients have asked about problems associated with prophylactic oophorectomy, and in general, fertility is a major concern for both breast and ovarian cancer patients as well as *BRCA* mutation-positive patients. They also believe that fertility preservation should involve a multidisciplinary team of health care professionals, including oncologists, reproductive endocrinologists, and fertility preservation specialists, as well as obstetrician/gynecologists, surgeons, radiation oncologists, and social workers and genetic counselors.

Inconsistencies in Genetic Counselor Attitudes and Actions

Despite believing that genetic counselors should discuss fertility preservation with their breast and ovarian cancer patients, including those who are *BRCA* mutation-positive, only 17.9 % said that they often or always discuss egg or embryo cryopreservation with these patients. Even fewer genetic counselors (8.5 %) discuss ovarian tissue cryopreservation. The same trend is seen in genetic counselor patient referrals to fertility specialists: 98.7 % of genetic counselors believe cancer patients should be offered a referral prior to treatment, yet only 11.1 % of genetic counselors often or always refer cancer patients to a fertility specialist prior to treatment. These numbers are slightly higher for *BRCA* mutation-positive patients, with 33 % of genetic counselors expressing the belief that fertility preservation should be considered prior to prophylactic treatment and 23.1 % of genetic counselors often or always discussing embryo or egg cryopreservation. For referrals to a fertility specialist, 16.7 % of genetic counselors often or always refer their *BRCA* mutation-positive patients and 35.2 % refer when the patient is considering a prophylactic BSO.

Barriers to Discussions of Fertility Preservation by Genetic Counselors

The major barrier that prevents more frequent discussion of fertility preservation in genetic counseling sessions is the fact that breast and ovarian cancer patients are seeing genetic counselors after cancer treatment (reported by 79.7 % in the Volk et al. study). Only 29.5 % of genetic counselors reported seeing breast and ovarian cancer patients prior to cancer treatment [19]. Ideally, discussion of fertility preservation should occur before cancer treatment. When genetic counseling sessions are held prior to cancer treatment, genetic counselors can integrate fertility preservation into the cancer treatment options discussion and facilitation of patient decision making.

Genetic counselors also cited timing as the number one barrier to discussing fertility preservation with *BRCA* mutation positive patients. Genetic counselors can discuss management options such as prophylactic BSO with their *BRCA* mutation-positive patients; again, this would be an optimal time for discussing fertility preservation options. While the majority of genetic counselors (78.5 %) reported that *BRCA* mutation-positive patients choose not to undergo prophylactic treatment, including prophylactic BSO, for those that do select this procedure prior to completing their family, genetic counselors can use their unique skill set to integrate fertility preservation information into genetic counseling sessions prior to surgery.

Conclusion: Genetic Counselors Can Bridge the Oncofertility Information Gap

The goal of oncofertility is to balance life-preserving cancer treatments with fertility preservation options. Gaps in information, data, and options have led to an unmet need for preserving fertility in patients with cancer. The information gap, in particular, involves a lack of cancer patient education about fertility impairment associated with cancer treatment and fertility preservation options. As few as 34 % of reproductive-age women treated for cancer recall discussing the effect of cancer treatment on fertility [5], yet NCCN guidelines for young adults with cancer state that fertility preservation should be an essential part of cancer management and the effects of treatment on fertility should be discussed at the time of diagnosis [7]. The oncofertility information gap can be attributed to the healthcare provider's desire to start treatment immediately, lack of adequate knowledge regarding fertility preservation, and insufficient communication and counseling skills.

The oncofertility information gap can be addressed with the implementation of a multidisciplinary approach to fertility preservation. Many patients have emphasized the importance of having access to not only fertility specialists and oncologists, but also psychological support and counseling [6]. Meeting this need has led to recommendations for a healthcare worker with special training to address the sensitive topic of fertility preservation separate from the often overwhelming initial oncology consultation [12].

According to Volk et al., genetic counselors believe that fertility preservation discussions are important and that they are a part of the genetic counselor's role in cancer care [19]. Genetic counselors possess the necessary skills to bridge the oncofertility information gap with their patients—those who have a personal of family history suggestive of familial or hereditary cancer. The four critical domains that genetic counselors contribute to the cancer care team are communication skills, critical thinking skills, psychosocial assessment training, and professional ethics and values [13]. Unlike the traditional treatment-based discussions with patients, genetic counselors use a nondirective, patient-centered counseling approach to facilitate shared decision making.

The NCCN guidelines for young adult cancer recommend a genetic and familial risk assessment within the first 2 months after the start of treatment [7]. However, because timing of cancer treatment is identified as the number one barrier to genetic counselors' ability to discuss potential threats to fertility and fertility preservation options, healthcare providers should refer young women diagnosed with cancer to a genetic counselor prior to cancer treatment. Genetic counselors have a unique skill set that allows them to discuss options, facilitate decision making, and make valuable psychosocial assessments that may underlie cancer treatment and subsequent fertility preservation. Genetic counselors can use their skill set to effectively bridge the oncofertility information gap for patients with a personal or family history suggestive of a hereditary or familial cancer.

Acknowledgements This work was supported by the Oncofertility Consortium NIH 5UL1DE019587 and the Specialized Cooperative Centers Program in Reproduction and Infertility Research NIH U54HD076188.

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