

Oncofertility Education Resources: A Team-Based Approach to Expanding Access to Oncofertility Services Worldwide

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Although faced with the inherent stresses of a new cancer diagnosis, many cancer patients list future fertility as one of their most important concerns (1-3). After a new cancer diagnosis, patients are focused on understanding their prognosis, their impending treatments, potential financial burdens, and family and work obligations. However, many young people diagnosed with cancer also have significant concerns about their future fertility. Cancer survivors recall that fertility concerns were influential enough to alter their cancer treatment decisions (4-6). Not only can fertility concerns have a substantial impact on patients at the time of diagnosis, but they can also have an impact years later. Several studies have indicated that cancer survivors who are infertile due to their treatments are more likely to suffer from emotional distress (6-8). Discussions about fertility preservation are most beneficial when they occur as early as possible after the cancer diagnosis. Oncologists are urged to provide a fertility preservation consultation or referral in a timely manner to mitigate long-term health consequences associated with cancer treatment (9). Unfortunately, few cancer patients have the opportunity to discuss fertility issues with their oncologist or are referred to a reproductive specialist at or soon after their diagnosis. Both provider- and patient-related issues contribute to the poor communication of fertility concerns and preservation options (10-17). Provider barriers include a lack of knowledge of the impact of cancer therapies on fertility and lack of resources for referring patients to reproductive specialists. A team-based approach towards fertility preservation and increasing provider and patient awareness of professional society guidelines and educational resources will improve patient outcomes, as described below.

A Team-Based Approach

The primary goal of a clinical oncofertility program is to help cancer patients and their physicians discuss fertility preservation options soon after diagnosis, but before treatment begins, to consider the impact of their cancer treatment on future fertility, and to ensure that cancer patients are given the best opportunity to achieve their fertility goals. Oncofertility programs must provide physicians and patients with timely and comprehensive fertility preservation information, as well as efficiently coordinate the care of cancer patients between healthcare providers in oncology and reproductive endocrinology. A successful oncofertility program requires the establishment of a multidisciplinary team that includes medical specialists (e.g., oncologists, hematologists, rheumatologists, reproductive endocrinologists, urologists, surgeons, anesthesiologists, and pathologists) and their staff, nurses, patient navigators, genetic counselors, mental health counselors, the embryology and andrology lab team, and the scientific research team (Figure 1). In both domestic and international settings, this large team must work together to best meet the fertility needs of each cancer patient. To do this, oncofertility team members must understand the importance of quick, early fertility preservation referrals prior to cancer treatment, the unique fertility needs of young oncology patient, and how to refer a patient between members of the oncofertility team. Establishing and maintaining multiple lines of communication between various stakeholders is essential to the success of an oncofertility program and comprehensive patient care.

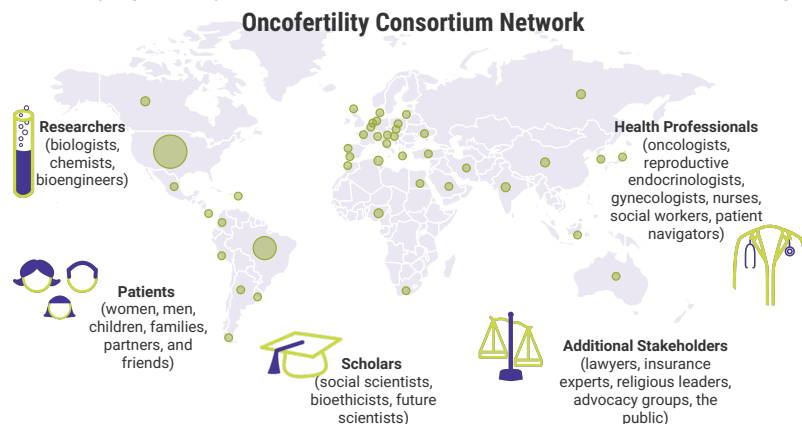


Figure 1: The multidisciplinary, international oncofertility team-based approach.

Establishing Global Communities of Practice

One of the best examples of how a formalized international fertility preservation infrastructure can provide integrated patient care is the Oncofertility Consortium. To facilitate the sharing of knowledge and resources, the Oncofertility Consortium established the National Physicians Cooperative in 2007 (NPC) and the

Oncofertility Global Partners Network in 2012 (18). The NPC is a network of more than 80 fertility preservation centers across the United States that are committed to fertility preservation. The NPC provides a collaborative forum for the exchange of ideas, clinical research methods, and technologies in basic reproductive physiology that may be translated directly to clinical medicine. It also provides a wide range of resources for oncology teams that treat young cancer patients, such as guidance on how to refer patients for fertility preservation, practical advice on how to navigate financial/billing issues, and information on new developments in fertility preservation research and practice that may affect patients.

In recent years, the NPC has expanded into an Oncofertility Global Partners Network that includes members in 40 countries around the globe (18). Members of this international group receive tools, including all of the Oncofertility Consortium's existing online educational materials, and guidance to set up their own local consortia. Members are encouraged to translate these materials to their native languages and to disseminate them throughout their provider and patient networks. An individual patient's oncofertility team is chosen based on patient demographics, cancer diagnosis, the planned cancer treatment, location, available providers, and available facilities and agencies. Additionally, members of the global community collaborate on a number of research projects and studies. This work has resulted in four partner-wide publications, which examine the current state of oncofertility on a global level, examine challenges and barriers to success, and identify future opportunities for growth (18-21).

As of 2018, the NPC and the Oncofertility Global Partners Network have merged to form the Oncofertility Professional Engagement Network (OPEN). OPEN will build upon the past successes of the National Physicians Cooperative and Global Partners Network and continue to foster international and interdisciplinary collaborations. The NPC and Global Partners Network developed at different times and with different original needs. The current need is to unify the emerging technologies and best practices that emerge from rural communities to large metropolitan cities, both domestically and abroad, into a functional unit. OPEN will bridge this gap between domestic and international programs and in so doing create another corridor where members share resources, best practices, methodologies, and experiences. Such global expansion facilitates the coordinated effort of the oncofertility community to establish an evidence-based standard of care and to rapidly translate cutting-edge basic research into clinical practice.

Conference/Meetings

Although members of the oncofertility community interact often through email and other virtual means, it is still important to convene the field in-person on an annual basis. Since 2006, the Oncofertility Consortium Annual Conference has become a place where academics and clinicians, high school students to tenured professionals, all with multidisciplinary backgrounds, converge to share research and clinical advances and updates, review new and emerging technologies, and discuss future directives for the field (22). The Conference presents an opportunity for diverse teams of researchers and clinicians to showcase their scientific and clinical results and experiences, and aid them in incorporating this work into future endeavors. This annual event is a forum for senior faculty, junior faculty, students, and trainees to present their research findings and it provides our presenters and participants the opportunity to teach and learn from one another and engage with colleagues. Furthermore, the Conference offers many opportunities for training and professional development like a dedicated fellow education day described in more detail below. A notable accomplishment of the conference is how it brings together diverse attendees with a common goal. These meaningful interactions solidify membership in a community and remind our attendees that they are part of a larger mission that extends beyond their bench or bedside.

Fellow Education

As a team, members of the oncofertility community work together to identify knowledge gaps and look for ways to mitigate these knowledge gaps within the field. Clinical trainees desire, but lack standardized and coordinated fertility preservation and oncofertility curriculum (23). In an effort to mitigate this knowledge gap, members of the Oncofertility Consortium developed curriculum in partnership with the American Society for Reproductive Medicine and host an annual Fellow Education Day Symposium at the annual Oncofertility Conference. The purpose of the course is to educate fellows on fertility preservation and survivorship care for cancer patients across the reproductive life cycle. The course also models a team approach to fertility preservation care. Since its inaugural year in 2016, fellows from a variety of disciplines, including reproductive

endocrinology, urology, and oncology have participated in this course to enhance their knowledge about oncofertility.

Professional Society Guidelines

Oncofertility teams must stay current on published clinical guidelines, recommendations, and opinions of professional organizations involved with the care and treatment of fertility preservation patients. In 2006, 2013, and later updated in 2018, the American Society for Clinical Oncology (ASCO) convened a multidisciplinary panel that drafted and issued guidelines on fertility preservation for cancer patients (24-26). 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” (25, 26). While clinical judgment should be employed in determining when to raise issues of fertility and fertility preservation with patients, having this discussion at the earliest possible time is encouraged. If members of the oncology team feel comfortable discussing fertility in more detail, the ASCO guidelines provide additional “talking points” (25, 26). These points may be discussed early after diagnosis, as patients decide whether to pursue a fertility preservation consultation, or later in the process, if patients request their oncologist’s opinion regarding their fertility preservation options.

Other professional societies and organizations, such as the ASRM, the Association of Pediatric Hematology/Oncology Nurses (APHON), the American Academy of Pediatrics (AAP), FertiPROTEKT, and the International Society for Fertility Preservation (ISFP) have also developed guidelines and educational resources designed for patients and providers (24, 27-30). Although many of these professional society guidelines have distinct audiences, the general goal is to provide clinicians and other health professionals with evidence-based recommendations based on age, sex, and treatment. They also provide professional guidance on established fertility preservation techniques and patient counseling. Improving providers’ awareness of these guidelines and resources will consequently improve patient awareness of cancer-related fertility concerns and facilitate timely 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 (31). Once a patient has been referred, the reproductive specialist should also provide a comprehensive consultation to interested patients, detailing all appropriate fertility preservation treatment options, risks of their cancer or cancer treatment to fertility, and pregnancy after cancer.

Oncofertility Implementation Strategies

When implementing an oncofertility program, the goals are to decrease decisional conflict for the patient, improve patient satisfaction, and allow patients to make well-informed decisions. A major step in this direction is to improve patient and provider awareness about fertility preservation because knowledge and understanding of disease and treatment are closely linked to patient outcomes and quality of life. Here we highlight the numerous educational resources that are available to patients and providers.

Resources and Tools

The development of innovative communication approaches is essential for further improving provider and patient understanding of their fertility preservation options, especially in the challenging context of a recent cancer diagnosis. In these settings, patients are asked to process a great deal of complex medical information with often-limited knowledge of reproduction and fertility. This includes six textbooks (32-35), online educational videos, basic science curricula, and other tools for providers and patients to learn more about oncofertility. Print and web-based interactive educational tools and decision aids directed at patients may further improve access to fertility preservation information and allow for higher decisional satisfaction for reproductive-age cancer patients. Not surprisingly, patients who sought out informational websites prior to their fertility preservation consultation had greater pre-visit knowledge than those who did not seek out this information (36).

The Oncofertility Consortium, together with other advocacy groups, have also developed various authoritative websites and pamphlets that can be easily accessed by both patients and providers to navigate the process and facilitate discussions and decision-making (Table 1). Patients can visit various web sites to learn about how cancer may affect their fertility, what current clinical options are available, where to obtain the best care, and how to find support. Providers can keep abreast of basic research advances, find information on how to

establish a fertility preservation program, and determine where to refer a patient. Complementary print-based materials are linked to these web-based resources. For example, the Oncofertility Consortium has published multiple books on fertility preservation that cover diverse topics, including the overall scope of the reproductive considerations for cancer patients and research; legal, ethical, and religious considerations; clinical and medical practice for providers; communication strategies for the field; oncofertility in a pediatric setting; and fertility preservation and non-oncologic conditions. Importantly, many of the educational resources have been translated into Spanish, Italian, Portuguese, Chinese, French, Korean, Turkish, and Japanese to ensure broad distribution of information globally.

Perhaps unanticipated in the early days of oncofertility was the need to establish an accessible language by which males and females could understand reproductive health terminology and concepts to better engage in discussions with their healthcare providers about their fertility preservation options. To this end, members of the Oncofertility Consortium developed a series of tools that can easily be integrated into fertility preservation care to educate individuals about fundamental topics in reproductive biology (Table 2). For example, “A New You, That’s Who” is a childhood reproductive education project that teaches children (ages 10-14) the basics about reproductive health through songs and animation (37). A Massively Open Online Course (MOOC) is also available to provide college-aged students and beyond with a virtual crash-course in topics including reproductive anatomy, puberty, sexual biology, contraception, reproductive disorders, and oncofertility (38). Finally, the Repopedia has been established as a comprehensive and authoritative lexicon of reproductive terminology that is targeted to audiences of all ages and can be hyperlinked to any website to supplement reproductive health education and learning.

Fertility preservation is now a well-recognized field marked by its own societies (e.g., Oncofertility Consortium and ISFP) that support annual international conferences to disseminate advances. To keep the global community engaged throughout the year in emerging research and clinical services, the Oncofertility Consortium has also developed Virtual Grand Rounds. In this model, an unlimited number of researchers, clinicians, and others participate in monthly presentations that are broadcasted virtually, and viewers can ask text-based questions that are answered in real time. This format allows the oncofertility community to act quickly to develop shared practices within the expanding community. Together, these resources represent a new generation of learning tools that have been instrumental in the expansion and successful implementation of fertility preservation across the globe.

Table 1:

Patient and Provider Resources	
American Cancer Society	http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/sexualsideeffects/women/index (Women) http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/sexualsideeffects/men/index (Men)
Fertility Authority	https://www.fertilityauthority.com/
FertiPROTEKT	http://fertiprotekt.com/
Cancer Knowledge Network	https://cancerkn.com/
National Cancer Institute	http://www.cancer.gov/types/aya
Bright Pink	https://www.brightpink.org/
Resolve- The National Infertility Association	http://www.resolve.org/
Cancer Legal Resource Center	https://disabilityrightslegalcenter.org/cancer-legal-resource-center
LIVESTRONG	https://www.livestrong.org/we-can-help/fertility-services
stupidcancer	http://stupidcancer.org/
Fertile Action	http://www.fertileaction.org/
Imerman Angels	http://imermanangels.org/
Alliance for Fertility Preservation	http://www.allianceforfertilitypreservation.org/
Center for Young Women’s Health- Boston Children’s Hospital	http://youngwomenshealth.org/topics/gyn/#cancer
Hope for Two	http://www.pregnantwithcancer.org/

Cancer and Careers	http://www.cancerandcareers.org/
Coalition to Protect Parenthood After Cancer	http://protectparenthoodaftercancer.org/

Table 2:

Oncofertility Consortium Resources	
Website	Web Address
Oncofertility Consortium	http://oncofertility.northwestern.edu/
Oncofertility Consortium Blog	http://blog.oncofertility.northwestern.edu/
SaveMyFertility	http://savemyfertility.org/
Patient Navigator for Fertility Preservation	http://preservefertility.northwestern.edu
FERTLINE	http://oncofertility.northwestern.edu/fertline (866) 708-3378
Clinic/Center Explorer	http://oncofertility.northwestern.edu/find-a-clinic-or-center
Reprotopia	http://reprotopia.northwestern.edu
Reproedia, a Reproductive Health Lexicon	http://reproedia.org
Oncofertility Virtual Grand Rounds	https://oncofertility.northwestern.edu/resources/oncofertility-virtual-grand-rounds
Massive Open Online Course (MOOC)	https://www.coursera.org/learn/reproductive-health

Summary and Future Outlook

Fertility preservation is a dynamic field in which patient needs are continuously evolving, thereby accelerating the need for solutions from integrated teams. We will best serve patients in need of fertility and endocrine preservation by using new communication strategies that improve the awareness and understanding of all key stakeholders, through innovative tools, basic science collaboration, global partnerships, and sister organizations with thoughtful and intentional dialogue. As more patients seek and undergo fertility preservation, we are also at the precipice of big data on outcomes. The need for patient registries has been hotly debated in the oncofertility domain. Physicians badly need data to guide practice management plans, and efforts have been made to develop registries. For example, the FUTuRE (Fertility Understand Through Registry and Evaluation) team has established the first Australasian Oncofertility Registry that collects international data from cancer and fertility centers (39, 40). Outcomes for this registry include uptake and use of fertility preservation. However, the fragmented nature of the health care market, small sample sizes, costs to maintain and mine the data, limited participation among patients and providers, and lack of completeness of self-reported data remain important challenges (41). If these challenges can be addressed, the development and implementation of registries represent an opportunity for the field moving forward.

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