

Preface: Communicating Reproductive Science

This is the fourth book in a series that has examined the development of a new field: “Oncofertility.” Our purpose in creating this new term was to communicate a simple concept: that fertility preservation for cancer patients is imperative to oncology doctors *and* to fertility doctors. The intention of a new word, without hyphenation, was to illustrate that solidarity. Oncofertility has entered the lexicon, but whether it surpasses the term that is otherwise used—“fertility preservation”—will be borne out by time.

Oncofertility arose from our recognition of the needs of young cancer patients and the development of technologies to mitigate the inevitable loss of reproductive function in some treatment settings [1]. Approximately 140,000 Americans under the age of 40 are diagnosed with cancer each year [2]. While many patients have a good prognosis, depending on the diagnosis and treatment regime, the impact on fertility can be significant. At the outset of our work in 2007, fewer than 50 % of cancer patients were receiving adequate fertility information before starting treatment [3–5]. In centers where strong fertility preservation programs exist, that number is now upwards of 80 %. We know that physicians want to provide every option for a healthy recovery for all of their patients. Helping physicians and patients stay abreast of the latest services and breakthroughs in fertility preservation will require authoritative, cutting-edge, and mobile resources.

The first book in this series (Oncofertility, Ed. Woodruff, Snyder, 2007) was written at a time when most patients were not receiving formalized information at the time of diagnosis about the fertility threats posed by the life-preserving cancer treatments they would soon be receiving. The book outlined the basic science activities that would “span the gap of knowledge” about fertility concerns in cancer and described some of the new basic science work that would ultimately provide additional options for patients [6]. The second book examined issues in Oncofertility associated with the law, economics, religious concerns, ethics, and education (Oncofertility, Ethical, Legal, Social and Medical Perspectives, Ed. Woodruff, Zoloth, Campo-Engelstein, Rodriguez, 2010) [7]. This compendium of “the humanities”

represented important thinking about the concerns of the *public* regarding the use of new fertility interventions and the needs of patients and their families for real-time data. The third book in the series was an important summary of the latest thinking on the medical practices necessary to provide fertility preservation options to cancer patients (Oncofertility Medical Practice, Ed. Gracia, Woodruff, 2012) [8]. When that volume was released in 2012, the medical community not only embraced the concept but also actively asked for more information—with none of the reluctance we faced from the medical community in 2007. This final book, on communicating fertility preservation topics, is the last that we will write as a team. The contents represent some of the best thinking from a group of transdisciplinary investigators who unified their efforts under a pioneering research consortium grant from the NIH that asked the scientific community to tackle “the most intractable biomedical problems of our day using teams” [9]. Oncofertility was an intractable problem at the time this book series started; because of tremendous advances in basic science, our tenacity in addressing critical issues of ethics and law, our investments in medical practice descriptions that help busy clinicians provide Oncofertility care, and our commitment to making sure every voice was heard through unique communication platforms, we did “not lose time or momentum” in achieving our goals. We have done what we set out to do and at the end, I believe that patients’ needs are now being addressed and the outcome that we measure is their ability to retain reproductive capacity and have a family one day.

As the reader will see, one of our main goals was to develop a suite of tools necessary to communicate information across disciplines rapidly. At the outset of our work, we set out several principles of technology development that were meant to guide our thinking. The first principle is that technology implementation and delivery is a collaboration between people, ideas, message needs, and infrastructure and that the methods and tactics should match the need. We also agreed that creating a robust interdisciplinary intellectual environment depends on a common language—a set of terms, ideas, and methods of work that everyone can understand. We also posited that the needs and expectations of the medical enterprise (patients and providers), research enterprise, and community vary but can be integrated into a seamless product. In following these principles, our hypothesis was that technology (anthropomorphically) participates in the work, and in doing so can increase the pace and quality of the communication activity. We believe that this hypothesis has been proven and a few products and tangible outcomes of our work are described in the chapters that follow.

Some of the products that I am most proud of include our Oncofertility Website (oncofertility.northwestern.edu), which was developed as an authoritative resource for professionals and was partnered with our “patient, parent, and partner” Website, myoncofertility.org. The Website offers information protocols for basic scientists, patient data sheets for providers, law reviews and ethics discussions, and videos that tell the Oncofertility story over time, and it also acts as our social medial hub (Facebook, blog, Twitter feed, etc.). We are neither an advocacy group nor a for-profit enterprise. Our purpose is to ensure that we are good stewards of the knowledge that we develop in the academy and that we communicate this knowledge in a

way that can be understood by patients, providers, and researchers alike. Our materials are provided in English and Spanish (at minimum) and more translations are taking place every day. Our materials were built with mobile compatibility (responsive design). We also built a standalone app and microsite for our iSaveFertility pocket guides for physicians and fact sheets for patients (savemyfertility.org). These guides can be used in the consultation room and help provide the continuity of information necessary for patients to make the urgent decisions that are necessary in the context of cancer diagnosis and treatment. We link these materials to the general public through CME activities at our annual international Oncofertility Conference, which includes presentations from thought leaders, patients, and the next generation of research and clinical trainees. Our poster session has been equally innovative, using 54" monitors to display movies, surgical procedures, and animations in a way that lets attendees learn and grasp complex information—in many cases outside of their field of expertise—quickly and memorably. We've also used communication technology to link research labs such that our work can be shared in real time with other expert labs. No single lab will ever make all of the discoveries entirely on its own—certainly not at the pace that I believe we need to move—and these technologies have permitted us to conduct team research on a truly global scale. Thus, we have moved beyond the ordinary process of discovery and publication to embrace multi-platform communication as an integral part of our work leading up to publication. This is a completely new way of thinking about basic science!

Finally, we recognize that the terms that we use are sometimes inaccessible because they are frankly unfamiliar or because people are “nervous” about reproductive terminology and think they should “know” concepts like “luteal phase” or “capaciation” and are afraid to ask. To address this issue, we created a communication tool called repropedia.org, a wiki that provides definitions of words within the context of any blog or Website. The API for repropedia can be linked to any Website, thus making those terms accessible and improving the knowledge of reproductive science for all of us.

You will be introduced to these and many more tools in the pages of this book. As this is the last book of its kind, I want to thank my co-editors Kate Waimey Timmerman and Marla Clayman for their vision and inventiveness in the development of our communication strategy and for ensuring that our blogs are filled with the latest information presented in ways that our community can best use it. I also want to thank the co-editors from the other three volumes, Karrie Snyder, Lisa Campo-Engelstein, Sarah Rodriguez, Laurie Zoloth, and Clarisa Gracia. Each of them has been an extraordinary partner during the 6 years of this grant process. I also thank the coPIs of the original roadmap grant—Lonnie Shea, Richard Stouffer, Mary Zelinski, Jeff Chang, Kerry Snyder, Clarisa Gracia, Marla Clayman, Kathleen Galvin, Kemi Jona, Gwen Quinn, and Christos Coutifaris. They have been passionate in the pursuit of better fertility options for cancer patients and patient with a big, multidisciplinary grant that took much more effort than an individual R01. I also want to thank my former student, friend, and scientific editor extraordinaire, Stacey Tobin. She has helped me communicate my ideas without grammatical error in a tireless way. She is a great communicator.

Finally, this book and all that it represents is dedicated to the patients we serve who have ever had to worry about fertility in the face of cancer. While the true mortality associated with cancer has been somewhat mitigated by the advances in cancer treatment, the existential crisis associated with that devastating diagnosis still exists, especially in a young person with all the expectancy of a future life and family. My hope is that in some small way, we have contributed to the lives of these patients by enabling a field that relies on interdisciplinary teams to solve problems and then work together to get these concepts into practice. I don't know of another example where translation of ideas became tangible so quickly. One would be hard-pressed to find an oncologist today, in 2013, who is not aware that a young person facing a cancer diagnosis wants to not only beat the disease but also return to the life that they once had—with the fullness of life and family. Oncofertility is a word, a field, and a hope for us all.

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Oncofertility Communication

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