Oncofertility Communication

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As a 17-year young adult survivor of brain cancer whose life plan and career path were eviscerated by the disease, I speak from experience as someone who recognizes the overwhelming mandate to disrupt and rethink our deeply flawed health-care system. Now more than ever, the next generation of patient/caregiver stands the most to lose without the imperative of improved—and thusly more meaningful—communication with their providers.

Young adults are not special but they are different, with unique and underserved issues that present significant barriers to improved patient outcomes. This new, young, and empowered citizen is a different breed of consumer who demands the latest in sophisticated Web tools and mobile tech, access to trusted patient networks like StupidCancer.org, age-appropriate aggregated support resources, and a medical team who “gets it” that cancer is a chronic disease and this is not 1995.

I applaud the few and proud innovators in medicine; the academic leadership who dedicate their sleepless lives trying to discover and implement best practices in OC communication. And while it’s easy to say “there’s still much work to be done,” that work is actually getting done. We have become the change we wished to see, and resultantly, the young adult cancer movement no longer has legs… it has wings.

New York, NY

Matthew Zachary
When someone first learns that he or she has cancer, the primary question that comes to mind is “will I survive?” Yet, at the time of diagnosis, it is critical that people also focus on their personal hopes and dreams for life after cancer, especially when the cancer treatments being considered or planned could dramatically alter one’s future. Such is the case with fertility. A number of the curative therapies for adolescents and young adults diagnosed with cancer have the potential to compromise sexual and reproductive function. Therefore, while these are difficult conversations to have, discussions about cancer treatments’ effects on reproductive capacity must occur alongside those about treatment itself, before exposure to any therapy; patients and families cannot wait until treatment ends to discuss whether to have children after cancer.

So how do you broach this deeply personal topic, for many still very much a taboo, at a time of such emotional turmoil? In this much-anticipated volume, over two dozen scientists and clinicians—pioneers in the evolving, young field of oncofertility research and practice—offer clear and thoughtful guidance about how to conduct these sensitive conversations. This guidance includes consideration of personal preferences, patient age, cultural values, health literacy, spouse and partner perspectives, physician attitudes, implications of genetic testing for decision-making, ethical/legal concerns, and the specific communication skills necessary for approaching and having productive conversations touching upon these complex topics. The growing array of tools (print, online, DVD, digital applications, phone, media) now available to inform both patients and providers about state-of-the-art techniques for fertility preservation is also highlighted. Importantly, the editors included chapters on two of the key barriers to successful communication about oncofertility: insurance challenges and lack of public awareness.

This volume is a natural outgrowth of the Oncofertility Consortium project, a unique collaboration funded by the National Institutes of Health as one of its Roadmap initiatives, and directed under the outstanding leadership of Dr. Teresa Woodruff. This new text complements and builds upon another highly acclaimed product of the project, the rich Website resource http://MyOncofertility.org.

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It is unlikely that the founders of the National Coalition for Cancer Survivorship were thinking specifically about the oncofertility concerns of the growing population of cancer survivors when they redefined what it meant to be a “cancer survivor” in 1986. Indeed, across the US at that time, we hardly spoke about cancer, much less anything to do with sexuality or intimacy. At that historic coalition meeting in Albuquerque, New Mexico, this intrepid group of individuals, which comprised survivors, clinicians, service delivery leaders, and advocates, argued that we should no longer adhere to the medical definition of what it meant to be a survivor, which held that an individual had to remain disease-free for 5 years after treatment to be called a survivor. They advocated that an individual should be considered a survivor from the moment of diagnosis and through the balance of life, regardless of the cause of death. With this definition change, they wanted to accomplish two goals: to send a clear message of hope to those newly diagnosed that there could be life after cancer; and second, most critically, they wanted to change the philosophy of cancer care. Specifically, they wanted to be sure that patients and oncology clinicians took the time at the outset of care to talk about the potential impact of cancer and its treatment on each individual’s life and the options available for simultaneously ensuring the best chances for survival and a rich and valued future life.

This new volume is a testament to the revolution we have seen in the care of our growing population of survivors. While geared more for the research and clinical community, the topics covered are likely to be of great interest to diverse audiences. Indeed, it is my hope that, armed with the information contained in this work, cancer survivors, their healthcare providers, partners and loved ones, diverse advocates, and the broader public will feel equipped with the knowledge and skills they need to openly discuss and act on concerns related to the sexual and fertility consequences of having cancer. Given that well over a million individuals each year are diagnosed with cancer as children or during their childbearing years, the human and deeply life-affirming impact of this work has the potential to be quite profound.

Bethesda, MD Julia H. Rowland
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 “capacitation” 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 co-PIs 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.

Chicago, IL, USA

Teresa K. Woodruff

References

Preface: Oncofertility Communication as a Model for Multidisciplinary and Patient- and Family-Centered Care

Communication is central to the human experience. With every technological advance, from telegraphs and telephones to mobile devices and webcams, people are able to communicate with others in ways that previous generations had not. Just as interpersonal communication has changed, mediated communication has undergone a radical transformation in the last two decades.

For patients, their families, and the healthcare system, these changes have accelerated patients’ ability to be involved in their healthcare. With the advent of the Internet and widespread adoption of devices on which to access it, individuals have greater access to health information as well as their social and familial networks than ever before. These may interact in a myriad of ways. Although there is still some concern about the “digital divide,” in many cases, the issue is not simply about access to information. Patients need provision of information that is reputable, comprehensible, relevant, and timely. In some ways, technology has made this task more difficult. Information may be available, but it is of uncertain value and voluminous. Simultaneously, reputable information can be found relatively easily (if one knows where to look) and passed along speedily.

Patient-centered communication in cancer care has been expressed as a goal for both compassionate and quality healthcare in general and cancer care specifically [1–4]. Yet achieving patient-centered care through communication is still an elusive goal. This book comprises the many types of communication necessary for optimal cancer and oncofertility care. First are the chapters about clinical and interpersonal communication: communication to and from patients, family members, and clinicians. Included in this part are tools designed for patients and their families to enhance their ability to participate in their care and guide in their decision-making. One of the things that makes this volume unique is that it is not focused solely on the communication needs of the adult cancer patient. In addition to explicitly addressing the needs of partners, other family-oriented chapters focus on the needs of pediatric cancer patients and their parents.