

Communicating Reproductive Science to a Doubtful World: Oncofertility as a Case Study

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Abstract (291 words)

In generating a communication strategy for The Oncofertility Consortium, we used three general guiding principles; presented here as tactics that may have value in other areas of our field. First, technology implementation and delivery is a collaboration between people, ideas, the message and infrastructure. Secondly, methods and tactics should match the need. Third, creation of a robust, interdisciplinary intellectual environment depends upon establishment of a common language between scientists, clinicians, scholars, patients and practitioners. While the needs and expectations of the medical enterprise (patient and provider), research enterprise and community-facing activities vary greatly, the tactics and methods below were integrated into a seamless product that provides value to the field. Investments of intellectual time and tangible dollars in this kind of work is paramount to increasing the pace, quality and reach of the work. If we, as a field, limit our research to publications in Biology of Reproduction, we will only reach a limited audience. If we wish to ensure translations of our work and ideas to the clinical setting, and if we wish to engage the public in the work that is supported by taxpayer dollars, new tactics are required. The following is a short description of the ways in which these concepts were put into practice in the development of the Oncofertility Consortium and the National Physicians Cooperative (NPC), the scientists and the practitioners providing fertility options to young cancer patients, respectively. The purpose of this editorial is to provide food for thought on how other reproductive science endeavors can be catalyzed by integrating technology into their work.

Oncofertility as a Case Study in Communication Methods (1664 words)

A general hypothesis for our overall field is that reproductive health underpins the overall health of women. Learning how ovarian follicle development is initiated, timed and can be harnessed allows us to better understand how ovarian hormones can best be controlled. By understanding the pathways by which the follicle informs the maturation of a healthy oocyte and its developmental sequelae, we will ultimately improve the lives of women, their offspring and thereby all people. If this hypothesis guides not only our science, but also the use of the science in clinical practice, and daily life, it is incumbent on us to communicate reproductive science in a way that both scholars and the public can understand.

As an exemplar or case study of communicating reproductive science, this article focuses on the tactics of The Oncofertility Consortium, a NIH funded grant that focused on the fertility needs of young women facing life-preserving but fertility-threatening cancer treatments. The first question one needs to answer in an editorial about 'communication strategies' is why 'make up' a new word? Doesn't this start the communication process off on the wrong foot? It is hard to imagine today how different the world was in 2005-2006. Oncofertility seems so obvious now – putting oncology and fertility care together – no hyphen to separate the two disciplines, but a blend of both disciplines in fertility preservation care in the cancer setting. REI clinicians most often use the term 'fertility preservation', but it creates a barrier to other disciplines. Cancer doctors don't think about reproduction, and don't really want to. So the intentional

inclusion of 'oncology' in the term provided a nexus for them as well as fertility specialists. No word better captured the notion that we could provide fertility options in medically-severe disease conditions better than Oncofertility. The word itself helped ignite a field and a grant. The word has served its purpose and may or may not go forward, depending on how the broader field now sees themselves – are they part of a continuum of care or are they fragmented into medical disciplines, with referrals out to other practices, forcing patients to figure out their own portals between oncology and fertility.

The Logo

After creating a new word to describe an emerging medical discipline, it is important to create an icon that serves as a central image for the program. The oncofertility logo is a combination of colors and intertwining dots and colors. These combinations embody the interdisciplinarity inherent in our program. The purple is the deep knowledge of self – who I am as a person – while the green exemplifies the hopefulness of tomorrow. The dots represent the eggs, sperm, embryos or tissue that is banked for the future and sweeps up into the graceful turn of the ribbon which then bows out in an subliminally 'expectant' state. Not every new idea requires a new name and logo, but in this field, it became a rally point and is used globally as a representation of a set of shared practices and guidelines. There is little doubt that the way we are providing care today will change tomorrow; that is how science and medicine work. In fact, it is our hope that the field of oncofertility is a short term solution to the off-target effects of cancer treatments. We hope that as cancer care improves, treatment effects will be more localized to the disease and impact neither hair follicle nor ovarian follicle and return the patient to health with intact reproductive function. Until that day, the logo serves as a reminder of the need to work together, using different methods that fit the needs of an individual with hopes for a fertile future.

Web Materials Designed to Solve Problems

The next question to address is what is the scope of the problem you are trying to solve? In 2012, there were 140,000 Americans under the age of 45 diagnosed with cancer. These young men, women and children have a good chance of survival because cancer drugs have become more effective and we are diagnosing the disease earlier. But data shows that few young patients receive adequate fertility information before treatment. In order to bring clinician up to date, we needed to create authoritative, multi media resources in order to assist in this rapidly developing area of work. We developed a number of tactics that created new tools for collaboration. These include our multilingual Oncofertility Consortium website for scientists, clinicians, patients, research scholars and our global partners. This site provides the main portal for news and information through our daily newsfeed, blogs, twitter and Facebook accounts. The website includes 'responsive design' to provide mobile compatibility with all electronic devices. The site is open (no login) to the public to ensure access to information is easy and rapid. Unrestricted file access to research protocols, equipment supply lists and the literature create value for a field where information can be fragmented and hard to derive autonomously. Teams from around the globe use the website as an easy template on which to build out their own programs. The website also houses archives of meeting materials and Virtual Grand Round talks. In order to reach the largest number of viewers, we believe that science has to move more into the virtual environment. Because we are a global community and it is challenging for everyone to come together in a physical room at a specific time, creating the venue for virtual talks and then archiving and disseminating the information fills this gap. By creating a central web-hub

we have lowered the barrier to groups by enabling a web-presence for their programs and assembling the existing and emerging information in our field. This catalyzes work and reduces the time between initiation and implementation.

Role of Social Media and New Generation Web Apps to Assist Clinicians

The social media intensive parts of the website provide a direct connection between the science and the advocates – an important part of the equation for future clinical research. One of the ‘rules’ of our social media program was that we would define all words that seemed too technical or represent anatomy or physiology that might be unfamiliar to the general public. This created a bit of a headache in the early days with words like ‘ovarian follicle’ defined over and over. To eliminate the curse of the parentheticals, we created a website called Repropedia: A Reproductive Health Lexicon that included short, authoritative, definitions for reproductive health terms. An Application Programming Interface (API) was created for the site so every word within our webpage and social medial materials has a floating definition that allows the reader to stay within the page and access reference materials as needed without leaving the parent site. To date, 137,035 unique users have accessed definitions on Repropedia. Repropedia was in the vanguard of using API’s for words; Wikipedia just recently deployed APIs on a number of websites. We hope to continue ensuring the words we use in reproductive science are clear and do not create confusion, which reduces the knowledge base of the general public about an area so critical to their health.

Focus on Cancer Patients, Parents and Partners

In addition to the main Oncofertility Consortium website, we created specific web tools for patients, parents and partners. These include a patient navigation site, fertilitypreservation.northwestern.edu, an iPhone App called iSaveFertility and its associated microsite SaveMyFertility.org. These sites were created expressly to ease delivery of materials to patients directly from a doctors’ office. This information is available in English and Spanish and providers can translate documents as needed to suit their patient population. Just as the general public is uncomfortable with discussing the physiological processes of reproduction, so are generalists and oncologists. These sites provide easy pocket guide information for these professionals to have authoritative data at their fingertips and deliver the material to their patients together with a referral. ‘Telesynergy’ is the final vehicle for delivery of material, which is targeted to community oncologists and primary care specialists through Virtual Grand Rounds. This program provides primers on topics such as ‘contraceptives in the cancer care setting’ or ‘case studies in oncofertility’ and offers continuing medical education credits for attendees. Since there is limited oncofertility information in medical textbooks at present, outside of those published through the Oncofertility Consortium, programs like these fill an education gap that will eventually be filled by traditional didactics.

New Tools for Basic Scientists

One of the failed strategies of the last century was the focus on the scientist as an autonomous unit. This concept was largely based on the need to identify faculty who would become ‘tenured’ under the academic achievement system begun in the mid-1800’s. Scientists had to work autonomously to demonstrate their independent creativity and ability to self-fund their work. The unintended consequence of this system was to limit the team-based science that is described here. We maintain ‘secrets’ about our work, worrying over publication times and strategies. With few exceptions, individual papers rarely succeed in changing the world. It is, in fact generally relegated to being read a few times. The strategy employed within the Oncofertility Consortium changed

this basic precept and encouraged open, shared lab meetings, both in-person and virtually, where free exchange of ideas ensured that ideas generated anywhere in the network could be discussed and then tested in other species or in other labs. The Virtual Lab Meeting (VLM) became an important part of the dynamic of the consortium where ideas and papers could be rapidly translated into the patient care setting. In addition, we created a lab-based system of sharing information called iExperiment. iExperiment was a way to connect the actual science in the lab, the ovarian tissue and follicles isolated from patients, presented in an online open format. This was my brainchild and while I think it has great potential this is a communication strategy that has not yet caught on. I think its time is on the horizon and will represent an eventual paradigm shift in the way we do work. Basic science is changing and moving faster than ever. Basic scientists require communication strategies that are keeping up with the latest technology so that science can be presented faster and in a way the new generation of learners can understand and adopt into their own work.

Inclusion of Ethics, Religion and the Law in Oncofertility

Before the first live birth from in vitro grown, alginate encapsulated follicles came a conversation with colleagues interested broadly in ethics, religion and the law. My sense at the time was that if we were to develop a field that was more than a publication, we would need to address all of the issues a patient might have at the time of making a fertility preservation decision including, what does my faith teach about reproductive interventions, who has rights to the tissue and who has ownership over time. This kind of thinking engaged a number of outstanding interactions with folks in the humanities and social sciences and I believe this lattice structure – reaching outward – helped with the movement up the authoritative ladder structure that is the ordinary route toward success.

Funding Communication Strategies

How did we fund these initiatives? Part of the funding came from the Oncofertility Grant itself. It was not necessary to build the various strategies that are described above, but it became increasingly clear that a plan was needed to ensure the work could be communicated broadly rather than locally. Portions of our work was funded by grants from Walgreens, Ferring, Merck and the Endocrine Society. It absolutely takes money to build websites and maintain daily blogs, but it also takes a commitment to the strategy. As the Director of the Consortium, I could have directed effort and money in a number of ways but it seemed that an experiment in clear communication strategies was a logical way to move our agenda forward. So we targeted a variety of sources to enable our success and made innovation and invention in communication methods a main mission of our program.

Communicating to the Next Generation

Since medical textbooks do not include oncofertility, we wrote five books to encompass the areas of basic science, ethics religion and the law, medical practice, communication strategies and the pediatric and disorders of sexual development populations. The hope is these books, which aggregate everything we know in the field, serve as a starting point for material that will become integrated into the major oncology, internal medicine and reproductive texts of our professions.

To influence the next generation of potential physicians and scientists, we used oncofertility as a teaching topic for high school students. This provided the basis for

teaching reproductive health, hormones and their functions, fundamentals of cell mitosis and meiosis, cancer biology, microscopy, biomaterials and the use of animals in biomedical research. By integrating these STEM topics into didactics at the university, in the schools and in libraries and museums, we hoped to influence the next generation of learners. As a consequence of this interaction, these students may become health care professionals, scientists or simply informed citizens. As long as they leave high school saying 'I like science and math', our job was accomplished.

Oncofertility and the Media

Perhaps no other topic can take a reporter more by surprise than oncofertility. Many times journalists call and are confounded by the very concept of fertility in the cancer setting. Uniformly they have stories of a family member or friend who faced cancer and fertility issues, but it never struck them, as it doesn't the general public, that reproductive science is working towards a solution to this problem. So, media outlets create an important part of the communication pipeline. We do not seek media for the purpose of touting ourselves, rather, it is a way to put a 'good face' on reproductive science and ensure that the public is aware of the emerging technologies that are shaping our reproductive health and future. One of the most interesting outlets for Oncofertility was an episode of 'The Young and the Restless'. It recounted the story of a young woman, facing a cancer diagnosis, begging to have her fertility preserved before treatment. In a cliffhanger, the patient escapes from the hospital and urges a friend to find fertility options. This portrayal of a patient advocating for herself still exists but because of the work through the oncofertility consortium it is becoming less and less frequent.

Conclusions

As a consequence of the NIH investment in this emerging area of science and e-medicine, we have field-wide advances in follicle biology, new tools for collaboration and mechanisms for increasing and sustain the pipeline. These outcomes will continue to be measured long after the last NIH report is submitted and it is hoped that these concepts can improve the field as a whole and ensure the health of reproductive science as a discipline, long into the future.