



Published in final edited form as:

*Narrat Inq Bioeth.* 2017 ; 7(2): 147–150. doi:10.1353/nib.2017.0044.

## Fertility Lost–Fertility Found: Narratives from the Leading Edge of Oncofertility

Teresa K. Woodruff, Ph.D.<sup>†,\*</sup>

<sup>†</sup>Center for Reproductive Science Northwestern University

### Abstract

A cancer diagnosis at a young age creates one of the most existential crises one can imagine. The good news is that for many of these young patients, they will survive their diagnosis. They will be told of the side effects of treatment including loss of hair but will not be told of the other losses associated with their reproductive function—loss of menstrual cycles, early menopause and the potential for pregnancy for women, loss of viable sperm for men, and loss of sexual libido in both cases. Not all cancer treatments result in the same series of fertility effects so one of the issues that physicians face is determining what the best course of fertility sparing options should be. That dilemma is in the best cases—in many more cases the patients are not told about the potential loss of fertility and are left with a myriad of financial and psychological decisions and costs that they navigate on their own. The stories in this symposium capture this unfolding series of events. Some cases result in good prognosis and fertility options that are appropriate and the patients are happy with the outcome. Others express regret and loss of potential now beyond their reach. As a practitioner in the field I find these narratives reinforce how important the broad research field of oncofertility is. These patients are at the forefront of emerging technologies and emerging medical interactions between disciplines that were miles away from each other. The stories illuminate the individual and the universal and are critical to the overall context of this field.

### Keywords

Fertility; Finances; Oncofertility; Baby; Cancer

---

I coined the term ‘oncofertility’ in 2006 to describe an area of basic research that spanned the traditional medical disciplines of oncology and fertility (Jeruss & Woodruff, 2009). We required a word because neither oncologists nor reproductive scientists were addressing the urgent unmet need that patients had for fertility management at the time of cancer diagnosis and treatment. Each specialist saw reproductive health as something the *other* should manage. This pointing across the aisle was not malicious but it did result in some of the anguish described in the narratives. Reading through the narratives of young cancer survivors reminds me how important the decision to provide a name for this thing—sterility, loss of the ability to have biological children due to cancer treatment—really was.

---

\*Correspondence concerning this article should be addressed to Teresa K. Woodruff, Ph.D., The Thomas J. Watkins Professor of Obstetrics and Gynecology, Center for Reproductive Science, Northwestern University.

The patient experiences described in the narratives represent the emergence of the field and so the stories are uneven—in some situations, fantastic care is provided and in others little or no discussion with professionals was available before, during or after treatment regarding hormone health, fertility options or issues concerning sexuality. These narratives create the story of an ongoing gap in the discipline where centers of true excellence, largely part of the Oncofertility Consortium National Physicians Cooperative (Bortoletto, Confino, Smith, Woodruff, & Pavone, 2017; Duncan et al., 2015; Oncofertility Consortium, n.d.) exist at our great academic medical centers, while the vast majority of hospitals lack linked services.

Here I explore the major themes of these contributed pieces as well as some of the contrasting experiences. I close with the insights presented by the narrative and the way these stories inform contemporary debates in the field. To be sure, these stories are filled with the raw emotion of having “*cancer*” as part of a life story and when coupled with lost fertility, the wounds are even more gapping. Reading these stories provides equal measures of empathy and determination to continue the work. I firmly believe that the promise of basic science in medicine is that tomorrow's patient will be treated better than today's. These narratives reveal the need to keep working.

## Theme 1: Financial Toxicity

Comments regarding the cost of fertility interventions were found in nearly every narrative. Financial toxicity is a term used to describe the impact financial issues have on patient outcomes (de Souza et al., 2017; Zafar, 2016). This issue is particularly problematic for the oncofertility cohort—many have not reached their economic peak and a cancer diagnosis can derail or halt education or career building opportunities that in addition to the extraordinary costs for cancer and fertility management can topple many survivors. Some of the comments include:

“...still in debt from the treatment, it was all too much.”

[Alexandria Yi]

“My insurance company refused to cover any of these costs because it did not consider the potential of infertility a medical necessity as I was not infertile yet. I had thousands of dollars of law school loans and shortly, I would endure tremendous unforeseen medical expenses, so I did not know where I would find the money to cover the fertility procedure.”

[Rijon Charne]

“There is a yearly fee for storage of the healthy sperm sample, and insurance does not pay for this. At the time, insurance also didn't pay for the doctor visit or sperm analysis. The out of pocket costs for this—on top of all the cancer bills—is quite overwhelming for anyone. I count myself lucky and grateful that my parents helped me defray the costs.”

[Bryan Ettinger]

“Money is the most uncomfortable and challenging aspect of our story. ... This is an unconscionable amount of money for anyone to spend let alone young people facing other costs due to cancer.”

[Erin McKinney & Robert Curran]

## Theme 2: Resentment and Regret

Each narrative reflected on the way the individual managed the emotions of the oncofertility diagnosis. Most of the emotions are raw and negative with few folks finding peace with the process or the outcome. A survey of younger adult female cancer survivors who were not advised about the fertility loss associated with cancer treatment found them to register at the post-traumatic stress disorder level (Canada & Schover, 2012). This is a sobering finding and these narratives reinforce how essential family building options are as a basal human emotion.

“I resent not being able to make an informed decision about a future pregnancy...”

[Grazia De Michele]

“Cancer unfairly took the choice away from me after I was diagnosed...”

[Tarah D. Warren]

“Regret is a powerful emotion, one that I am glad I do not have in this area.”

[Bryan Ettinger]

## Theme 3: Contrasting Experiences—Good and Bad Doctors

The contrasts within the narratives are between those who had *good* doctors and those who had *disengaged* or *bad* doctors. Oncologists and reproductive specialists received both designations so the burden and the credit is equally shared and not disproportionately placed at the feet of oncologists.

“...there was a complete disconnect with my doctor and I on the issue of fertility. He was focused on my cancer and failed to mention the repercussions of the treatment.”

[Alexandria Yi]

“It was not a topic that seemed to engage the medical team's attention, and we did not actually have many discussions with his doctors regarding this topic.”

[Mary Fauvre]

“...I was taken aback by her compassion...Her understanding of my infertility fears and her expertise regarding the urgency of freezing my eggs was remarkable.”

[Rijon Charne]

“From our first meeting, Dr. B was someone we felt we could identify with us, someone who would fight just as hard for our future as we were.”

[Erin McKinney & Robert Curran]

As an aside, there was one account of adoption.

“More than anything, I’m lucky that I don’t have to navigate the intricacies of today’s dating world as an infertile, menopausal, 27-year-old who is missing a kidney. I’m lucky that my extremely supportive boyfriend happens to be adopted and is open to building a family in one of the many other ways there are to do so.”

[Maggie Rogers]

Non-biological family building is something that needs more attention in this population, enabling parenting in a way that can be very satisfying. That said, ensuring that potential adoptive mothers with a cancer diagnosis have the opportunity to adopt remains an impediment despite the work of the Oncofertility Consortium on this topic (Gardino, Russell, & Woodruff, 2010; Quinn, Zebrack, Sehovic, Bowman, & Vadaparampil, 2015). As with other biologically based fertility interventions, non-biological family options need to be presented to families to mitigate or even eliminate the regret that is so evident in these narratives.

Surprisingly absent from the narratives, for me, were mentions of community—knowing other young cancer patients with similar concerns; comments about bringing awareness to the issue of cancer at a young age; and, discussion of the research environment surrounding care. The Oncofertility Consortium hosts patient advocates each year at our annual meeting and my calibration is from these individuals who may see the world through a prism that has been chiseled differently initially or been re-honed by their activism. I’m not sure which informs the other but I think it is important for the treating community to know that despite our best efforts, many individuals continue to self-navigate, encounter doctors that are insensitive to their needs, and are not aware of the most recent options for males and females and who are simply trying to make every day count.

Perhaps the most important insight from these narratives is the depth of human emotion associated with the loss of fertility. Cancer is devastating at any age but feels incredibly cruel when it strikes a young person. Infertility is associated with extreme anxiety in the general population (Lawson et al, 2014) and when compounded by the rapid action necessary to protect ovarian or testicular function before diagnosis—and/or if options are not extended, the long-term consequences of treatment are compounded. Provider awareness of this comorbidity of treatment—specifically infertility or sterility—needs to be better understood. Reproductive health lies in a strange netherworld between issues that affect one’s life and those that are categorized under quality of life (QOL). Based on these narratives and the many other oncofertility patients I have encountered, reproductive function needs to be categorized in a new way—perhaps as an *integrating life force*. The terminology may be clunky but it suggests a way for healthcare providers and perhaps even insurance providers to think about fertility concerns in a new way.

## Oncofertility: Promising Beginnings, a Long Way to Go

As noted above, there is no topic that is more in the crosshairs of oncofertility policy discussions than the issue of finances for oncofertility patients. The Oncofertility Consortium advocates with patient advocacy groups through (a) providing authoritative

research papers that argue pros and cons of insurance or detailing the pricing that inclusion of oncofertility patients in reimbursement plans require, and (b) advocating on capitol hill along with the American Medical Association (AMA) to consider oncofertility as a mandate in the same manner that breast reconstruction and wigs for cancer patients are listed as a federal mandate on insurance plans. Infertility coverage in the US is not universal and costs of interventions are quite substantial. This is true for general infertility patients as well and there are no professional or patient-based arguments being made to cap the costs. This elephant in the embryology lab must eventually be dealt with to make biological family building affordable.

Oncofertility as a word was born in 2006. Babies are being born today to young cancer patients. Oncofertility: the word is not hyphenated. This semantically demonstrates that both oncologists and reproductive specialists must be part of the solution to this emerging urgent unmet need. More and more patients, as well as specialists, are aware that options exist and that there is a need to act quickly to provide realistic options to preserve fertility and ensure that the psychological damage associated with fertility loss is mitigated. However not everyone is included in this medial reality. Our program began working toward a series of comprehensive solutions for young cancer patients but the work has taken time and as the narratives suggest, there are miles to go before everyone is included in this new medical tent.

## References

- Bortoletto P, Confino R, Smith BM, Woodruff TK, Pavone ME. Practices and attitudes regarding women undergoing fertility preservation: A survey of the National Physicians Cooperative. *J Adolesc Young Adult Oncol*. 2017; doi: 10.1089/jayao.2017.0016
- Canada AL, Schover LR. The psychosocial impact of interrupted childbearing in long-term female cancer survivors. *Psychooncology*. 2012; 21(2):134–43. DOI: 10.1002/pon.1875 [PubMed: 22271533]
- de Souza JA, Yap BJ, Wroblewski K, Blinder V, Araujo FS, Hlubocky FJ, Cella D. Measuring financial toxicity as a clinically relevant patient-reported outcome: The validation of the COmprehensive Score for financial Toxicity (COST). *Cancer*. 2017; 123(3):476–84. DOI: 10.1002/cncr.30369 [PubMed: 27716900]
- Duncan FE, Pavone ME, Gunn AH, Badawy S, Garcia C, Ginsberg JP, Woodruff TK. Pediatric and teen ovarian tissue removed for cryopreservaiton contains follicles irrespective of age, disease diagnosis, treatment history, and specimen processing methods. *J Adolesc Young Adult Oncol*. 2015; 4(4):174–83. DOI: 10.1089/jayao.2015.0032 [PubMed: 26697267]
- Gardino SL, Russel AE, Woodruff TK. Adoption after cancer: Adoption agency attitudes and perspectives on the potential to parent post-cancer. *Cancer Treat Res*. 2010; 156:153–70. DOI: 10.1007/978-1-4419-6518-9\_11 [PubMed: 20811831]
- Jeruss JS, Woodruff TK. Preservation of fertility in patients with cancer. *N Engl J Med*. 2009; 360(9): 902–11. DOI: 10.1056/NEJMra0801454 [PubMed: 19246362]
- Lawson AK, Klock SC, Pavone ME, Hirshfeld-Cytron J, Smith KN, Kazer RR. Prospective study of depression and anxiety in female fertility preservation and infertility patients. *Fertil Steril*. 2014; 102(5):1377–84. Epub 2014/08/27. DOI: 10.1016/j.fertnstert.2014.07.765 [PubMed: 25154674]
- Oncofertility Consortium. National Physicians Cooperative Map. 2017. Retrieved from <http://oncofertility.northwestern.edu/find-a-clinic-or-center>
- Quinn GP, Zebrak BJ, Sehovic I, Bowman ML, Vadaparampil ST. Adoption and cancer survivors: Findings from a learning activity for oncology nurses. *Cancer*. 2015; 121(17):2993–3000. DOI: 10.1002/cncr.29322 [PubMed: 26180029]

Zafar SY. Financial toxicity of cancer care: It's time to intervene. *J Natl Cancer Inst.* 2016; 108(5)doi: 10.1093/jnci/djv370

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript