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CANCER, INFERTILITY, AND THE NARRATIVE OF PROGRESS

*Sarah Rodriguez**

The four essays preceding this one each focused on aspects of the increasingly diverse and complicated area of reproduction. As the concluding essay in this Symposium Issue, I will weave these essays into my overview of cancer funding in the United States and my critique of the “progress against cancer” narrative.

Three of the essays examine fertility preservation for cancer patients to varying degrees, and so I will begin with the seeming outlier: Arshagouni’s *Be Fruitful and Multiply, by Other Means, if Necessary: The Time Has Come to Recognize and Enforce Gestational Surrogacy Agreements*, which is not explicitly about oncofertility. Rather, he argues for federal legalization of gestational surrogacy. A gestational surrogate, he states, “provides a noble service that should be respected and honored,” and the fact that such an act is not honored without “reservation” is, to Arshagouni, “mystifying.”¹ Arshagouni lays out at length the legal and moral arguments others have made against allowing gestational surrogacy and makes his case for why each of them comes up short. The compilation of studies he uses to illustrate that some of the fears of those who argue against gestational surrogacy—such as the fear that it will be detrimental to the child born in such a manner—are so far unfounded, and his addressing many of the legal and ethical concerns contributes to a more robust debate about this practice. But in his effort to illustrate that this form of reproduction is not the harmful or risky endeavor as argued by others, he does not address the possibility of harm or risk. Reproduction, in all its old and more recent methods, is based within medical,

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1. Paul G. Arshagouni, *Be Fruitful and Multiply, by Other Means, if Necessary: The Time Has Come to Recognize and Enforce Gestational Surrogacy Agreements*, 61 DEPAUL L. REV. 799, 847 (2012).

legal, physiological, social, familial, and economic understandings and relationships, making it an inherently complicated and complex endeavor.

Though gestational motherhood is a possible resource for some women who lose both their fertility and their capacity to bear a child as a result of cancer treatment, the remaining three essays all centrally concern fertility preservation and cancer treatment. Because of changes in cancer treatment, many people within (or before) their childbearing years who have cancer will either be cured or have their lives significantly extended, and many within this population are concerned about the impact their cancer treatments may have on their future fertility.² The preservation of fertility for young people before they undergo potentially infertility-inducing cancer treatments is a fairly recent development for oncologists to consider.³ Indeed, scientists are still investigating many of the emerging options within the field of oncofertility, in particular the options for women and girls not yet of reproductive age. These include whole ovary and oocyte cryopreservation as well as the freezing of ovarian tissue. For boys not yet of reproductive age, and thus unable to cryopreserve semen, investigational options include the freezing of testicular tissue.⁴

Health insurance itself is a relatively recent phenomenon, and even more recent is the legal mandate that certain procedures be covered by private health insurance.⁵ One of these more recent, and far from universal, mandates is coverage of assisted reproductive treatment by health insurance companies. In her commentary, Campo-Engelstein argues for the need for an extension of insurance coverage to include fertility preservation before cancer treatment as part of routine care.⁶

2. *Patient's Fact Sheet: Cancer and Fertility Preservation*, AM. SOC'Y FOR REPROD. MED. (Jan. 2004), http://www.asrm.org/uploadedFiles/ASRM_Content/Resources/Patient_Resources/Fact_Sheets_and_Info_Booklets/cancer.pdf.

3. See generally Jacqueline S. Jeruss & Teresa K. Woodruff, *Preservation of Fertility in Patients with Cancer*, 360 NEW ENG. J. MED. 902 (2009); Teresa K. Woodruff, *The Emergence of a New Interdiscipline: Oncofertility*, in ONCOFERTILITY: FERTILITY PRESERVATION FOR CANCER SURVIVORS 3 (Teresa K. Woodruff & Karrie Ann Snyder eds., 2007).

4. Mary E. Fallat & John Hutter, *Preservation of Fertility in Pediatric and Adolescent Patients with Cancer*, 121 PEDIATRICS e1461, e1463 (2008); Pasquale Patrizio & Arthur L. Caplan, *Ethical Issues Surrounding Fertility Preservation in Cancer Patients*, 53 CLINICAL OBSTETRICS & GYNECOLOGY 717, 718 (2010); see also Jeruss & Woodruff, *supra* note 3, at 909.

5. See generally PAUL STARR, *REMEDY AND REACTION: THE PECULIAR AMERICAN STRUGGLE OVER HEALTH CARE REFORM* (2011); see also PAUL OLIVER, CAL. HEALTHCARE FOUND., *STATE EMPLOYER HEALTH INSURANCE MANDATES: A BRIEF HISTORY* (2004), available at <http://www.masscare.org/wp-content/uploads/2007/05/CHCFEmployerMandatesHistory.pdf>.

6. Lisa Campo-Engelstein, *Commentary, Insurance Coverage for Cancer-Induced Conditions: Comparing Fertility Preservation Technology and Breast Reconstructive Surgery*, 61 DEPAUL L. REV. 849 (2012).

To do so, she compares the loss of fertility as part of cancer treatment with the loss of a breast for cancer treatment, asserting that because insurance companies pay for breast replacement surgery after cancer therapy, these companies should envision fertility preservation as part of this routine of care in order to create consistency and fairness in coverage.

While Campo-Engelstein argues for fertility preservation as a matter of fairness in insurance coverage for cancer patients, Cholst is concerned about the lack of regulation concerning another assisted reproduction option for women who have undergone cancer treatment: the use of donor oocytes.⁷ Cholst, speaking from the perspective of a clinician, is concerned that, while this form of reproduction is viable, it lacks regulation—a concern for both the donor and the recipient of the oocyte. She concludes, however, by noting that while patients need support to adjust to their cancer diagnosis and progress through their treatment, a “focus on technological solutions alone for quality-of-life issues,” such as the desire to parent, does not provide the patient with a full perspective.⁸

In her article, Roberts, too, is concerned with the focus on technological solutions. But while both Campo-Engelstein and Cholst touch upon the social context of oncofertility, for Roberts, the underlying social structures of injustice is central to any conversation about the ethics of oncofertility.⁹ I will return to Roberts at the end of this Commentary, and I am mindful of the larger social concerns Roberts and others have brought to the fore about fertility preservation, such as whether it reinforces the primacy of biological parenthood.¹⁰

But what I want to question in the remainder of this Commentary is the framing of fertility preservation technologies within the narrative of progress against cancer. In their recent article, Pasquale Patrizio and Arthur Caplan argue that on an individual patient level, so long as the standard of informed consent—with particular attention to the pediatric patient—is met, there should be no ethical issues in offering fertility preservation services to cancer patients.¹¹ But they, as well many others who have discussed fertility preservation, including the

7. Ina N. Cholst, *Oncofertility: Preservation of Reproductive Potential*, 61 DEPAUL L. REV. 763 (2012).

8. *Id.* at 774–75.

9. Dorothy E. Roberts, *The Social Context of Oncofertility*, 61 DEPAUL L. REV. 777 (2012).

10. See Shauna L. Gardino & Linda L. Emanuel, *Choosing Life When Facing Death: Understanding Fertility Preservation Decision-Making for Cancer Patients*, in ONCOFERTILITY: ETHICAL, LEGAL, SOCIAL, AND MEDICAL PERSPECTIVES 447, 447 (Teresa K. Woodruff et al. eds., 2010).

11. See Patrizio & Caplan, *supra* note 4, at 717–20.

author, place the emergence of fertility preservation technologies within the “progress against cancer” narrative.¹² Is it really progress to be considering preserving the fertility of a young person diagnosed with cancer nearly seventy-five years after the creation of the National Cancer Institute and forty years after the “war on cancer” was launched? Should we not primarily ask why a ten-year-old or twenty-five-year-old is even getting cancer—with rates of some common childhood cancers increasing—and what we should be doing to prevent this diagnosis?¹³

Cancer has a long history, but here I am concerned with the more recent development of our cultural acceptance of it within a biomedical and individual model: cancer is something we treat, either through surgery, chemotherapy, radiation, or some combination rather than something we collectively prevent. Beginning with the creation of the National Cancer Institute in 1937, the foundation of the biomedical model of cancer was established, and, though curtailed with the entrance of the United States in World War II, it rose again with the influx of even more funding soon after the war’s conclusion.¹⁴ The strong investment in science by the federal government during the war incited an interest in the expansive possibilities of scientific research among Americans.¹⁵ The push to fund biomedical research grew out of this larger cultural hope that the application of scientific knowledge could improve and lengthen lives; this belief grew not just from the advances themselves, but also in the belief in further advances and the unlimited possibilities of science.¹⁶ This economic investment, supported by cultural belief, in the potential of scientific and medical research profoundly altered Americans’ postwar health expectations by reinforcing the conviction that advancing scientific progress would

12. See Susan L. Barrett & Teresa K. Woodruff, *Gamete Preservation, in ONCOFERTILITY: ETHICAL, LEGAL, SOCIAL, AND MEDICAL PERSPECTIVES*, *supra* note 10, at 25, 31; Patrizio & Caplan, *supra* note 4, at 718.

13. Cf. PRESIDENT’S CANCER PANEL, REDUCING ENVIRONMENTAL RISK, 2008–2009 ANNUAL REPORT 111 (2010), available at http://deainfo.nci.nih.gov/advisory/pcp/annualReports/pcp08-09rpt/PCP_Report_08-09_508.pdf (“It is vitally important to recognize that children are far more susceptible to damage from environmental carcinogens and endocrine-disrupting compounds than adults.”).

14. See SIDDHARTHA MUKHERJEE, *THE EMPEROR OF ALL MALADIES: A BIOGRAPHY OF CANCER* 26 (2010); JAMES T. PATTERSON, *THE DREAD DISEASE: CANCER AND MODERN AMERICAN CULTURE* 137 (1987); David Cantor, *Introduction to Cancer Control and Prevention in the Twentieth Century*, in *CANCER IN THE TWENTIETH CENTURY* 5–6 (David Cantor ed., 2008).

15. See GERALD N. GROB, *THE DEADLY TRUTH: A HISTORY OF DISEASE IN AMERICA* 256 (2002).

16. See Judith P. Swazey & Renée C. Fox, *Remembering the “Golden Years” of Patient-Oriented Clinical Research: A Collective Conversation*, 47 *PERSP. BIOLOGY & MED.* 487, 487–88 (2004).

easily translate into medical progress, thus preserving and lengthening lives. Scientific developments created an impression of inevitable progress, with illness and disability no longer viewed as inevitable parts of life, but rather as problems to be overcome by scientific and medical advances. Americans' belief in the unlimited potential of science and its resultant medical advances was further influenced by dramatic changes in the social and economic situation for many Americans, in particular a rise in the standard of living. The combination of a higher standard of living and a belief in science (as well as its clinical applications supporting a longer life) resulted in Americans spending more on health care and a rise in the expectations of that care.¹⁷

Private organizations such as the American Cancer Society and, increasingly in more recent decades, the pharmaceutical industry also came to play a significant role in funding, thus establishing and reinforcing the biomedical model of cancer. Here, I simply note the increased funding allocated by the federal government to this model as a force behind the model.¹⁸ The U.S. government greatly intensified the funding of biomedical cancer research as part of the beginnings of a national medical research policy.¹⁹ Following World War II, the federal government dramatically amplified spending on cancer research: in 1947, \$14 million went to fund cancer research, and this grew to \$110 million in 1961, increasing to more than \$200 million in 1970.²⁰ In 1971, Congress and President Richard Nixon declared a "war on cancer," resulting in the federal government doubling the amount of biomedical research funding directed at the disease within one year. Indeed, this war saw a vast amount of money directed to the biomedical research of cancer: in 1973, \$500 million was allocated to the cancer research, then \$600 million in 1974, with another \$1.5 billion to be spent over the next three years.²¹ More recently, from 2005 through 2010, the budget for the National Cancer Institute has averaged \$4.9 billion annually.²²

I am not questioning the spending of this money on biomedical research, the resulting clinical advancements of which can be seen in the control of many manifestations of cancer, including testicular cancer and leukemia. I am not opposed to the biomedical model of cancer

17. See GROB, *supra* note 15, at 245; MUKHERJEE, *supra* note 14, at 121.

18. See R. F. Bud, *Strategy in American Cancer Research After World War II: A Case Study*, 8 SOC. STUD. SCI. 425, 431 (1978).

19. See GROB, *supra* note 15, at 256; MUKHERJEE, *supra* note 14, at 121.

20. PATTERSON, *supra* note 14, at 171–72, 245.

21. MUKHERJEE, *supra* note 14, at 188.

22. *Cancer Research Funding*, NAT'L CANCER INST. (June 2, 2011), http://www.cancer.gov/cancer-topics/factsheet/NCI/Fs1_1.pdf.

that focuses on the individual. But this model developed, and is today reinforced, largely at the expense of collective cancer prevention. And this is what I, following others before me, am questioning. This is not to say that cancer prevention has been absent. Indeed, prevention against cancer, with an emphasis on individual responsibility, has remained a popular goal, though an elusive one, since the beginning of the biomedical model of cancer.²³ In recent decades, increased attention has been devoted to examining behavioral factors as well as to genetic susceptibility to cancer.²⁴ With respect to some cancers this emphasis on personal behavior has worked, most notably the tie between smoking and lung cancer, just as it has in the case of early screening (such as with cervical cancer) or with determining genetic factors (such as with certain forms of breast cancer).

But despite a growing emphasis on genetic risk and lifestyle factors, the dominant model remains the biomedical approach to a diagnosed disease. Activists, especially within the last two decades and in particular environmental breast cancer activists, have begun questioning the dominant biomedical model of addressing the disease after it develops and instead argue for more attention paid to possible environmental factors as a means to prevent the occurrence of cancer.²⁵ Clinicians and scientists have also recently expressed concern about the effects of environmental factors; a recent President's Cancer Panel report was centrally concerned that the "true burden of environmentally induced cancer has been grossly underestimated."²⁶ Attention to the possible environmental factors places the responsibility for dealing with cancer not on individuals, but on the institutions responsible for exposure to carcinogens in our homes, workplaces, and communities, thus changing this model to include social structures as well as medical ones. And it refocuses the model of cancer from attention to the disease once it has occurred to prevention of it from occurring.

Perhaps the increased awareness of the possibility of infertility for children and young adults as a result of cancer treatments will initiate a discussion about the limits of this biomedical model of cancer. Perhaps the emergence of fertility preservation for children and young adult cancer patients will initiate a discussion about why young people are still getting cancer and thus increase the calls for research on the

23. GROB, *supra* note 15, at 260.

24. BARBARA L. LEY, FROM PINK TO GREEN: DISEASE PREVENTION AND THE ENVIRONMENTAL BREAST CANCER MOVEMENT 5 (2009).

25. LEY, *supra* note 24, at 30–31.

26. Letter from LaSalle D. Leffall, Jr., Chair, President's Cancer Panel, to President Obama, in PRESIDENT'S CANCER PANEL, *supra* note 13.

prevention of cancer, and perhaps that discussion will take into account the social structure factors over which individuals have little control. This, at any rate, is my hope.

But I worry that such optimism could be misplaced by our cultural love affair with technological interventions to endemic problems, both medical and otherwise. Instead of addressing the root of the problem, we may continue along with the biomedical model and search for a "cure" for cancer, accepting this as the definition of progress. I fear, then, that fertility preservation technologies for cancer patients could become one more example of the classically American solution to medical and social problems: a technological fix to provide a solution at the end, rather than acting to prevent a problem from the beginning. As Roberts so compellingly and forcefully argues both in this Issue and elsewhere, technological solutions to social problems often results in further oppressing already-disadvantaged groups.²⁷ Discussing this reliance on high-tech, end-point solutions rather than on prevention is where, perhaps, the conversation regarding fertility preservation should occur.

27. See DOROTHY ROBERTS, *KILLING THE BLACK BODY: RACE, REPRODUCTION, AND THE MEANING OF LIBERTY* 269 (1997).

