

Chapter 8

Placing the History of Oncofertility

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On Fertile Hope's website, Cathy, who at 35 was diagnosed with cervical cancer, shared her feelings and thoughts about her double diagnosis of cancer and infertility. At the time of her cancer diagnosis, Cathy had been married for 3 years and she and her husband had been trying to conceive for 2 years. Following their first attempt using Clomid and insemination, Cathy got pregnant with twins. Their joy abruptly ended, however, when 4 months into her pregnancy Cathy learned she had cervical cancer; her oncologist recommended an immediate hysterectomy. It was, she recalled a year later, "a total nightmare." Cathy and her husband lost the twins and the radiation therapy that followed destroyed her ovaries, putting her into early menopause. After her hysterectomy but before her radiation treatment, her gynecological oncologist asked Cathy if she wanted to harvest some of her eggs. When Cathy said yes, the couple underwent one in vitro fertilization (IVF) cycle before the radiation treatment began. That cycle resulted in six eggs which were fertilized, out of which four embryos were frozen for future use with a gestational carrier. Cathy told Fertile Hope that the whole experience had been devastating:

Not only did we try to get pregnant for 2 years, then lose twin babies, but I have lost my fertility permanently, and completely. I am in menopause as well. I feel like every last shred of my womanhood has been destroyed. To know that I'll never give birth, never be brought my baby in my arms as I lay happy and exhausted in a hospital bed, is a source of great pain. . . It is such an isolating feeling. I feel like I'll never be the same as other women. I don't see how life will ever be the same after this tragedy.

When asked by Fertile Hope what her one piece of advice would be to another cancer patient facing possible loss of fertility, Cathy said she would recommend doing "everything you can to preserve your fertility while you can," and stressed the importance of "speaking to a fertility specialist before you do anything that will permanently damage your ability to have children [1]."

As Cathy's story illustrates, cancer and infertility as a result of treatment are not defined solely by a medical diagnosis; they are also painful personal experiences occurring within a larger social and cultural context. I open with Cathy because in her narrative we find the medical, cultural, and personal – a microcosm of the emerging field of oncofertility.

Her story, like the story of oncofertility, exists now because of a convergence of many medical and non-medical factors, including, but not limited to, the following: changes in cancer research, diagnostics, and treatment; an increase in the number of younger people, and people like Cathy of child-bearing age, being diagnosed with, and surviving, cancer; a wider cultural acceptance of cancer as a publicly discussed and personally acknowledged disease; the infusion of public and private dollars into cancer as well as fertility/infertility research; recent developments in medical knowledge about fertility/infertility treatments; and a growing cultural acceptance of the use of assisted reproductive technologies (ART) like IVF. Additionally, Cathy's story and the story of oncofertility are part of the contested medical and cultural discussion on reproductive decision-making and the status of the fetus and embryo that has emerged in this country over the past several decades. The stories also reflect the transformations in medical and cultural understandings about pregnancy, birth, and fertility; changes in ideas about motherhood and the cultural importance of motherhood as well as the social role of women and what it means to "be" a woman; shifts in the dynamic of the doctor-patient relationship; and the consumer culture of both medicine, where some have health care and some do not, and babies, where some are able to afford fertility options while others are not. These ideas and events are among those which cumulatively brought forth oncofertility, and they will continue to overlap and influence each other as the field emerges. I will briefly draw out a few of these factors through Cathy's story, and by doing so will begin to present a picture for future work to contextualize the history of oncofertility.

Cathy's story could not have been told in 1909 or 1959. Indeed, in both of these eras, Cathy's physician may not have uttered the "C-word" to her. William Halstead, originator of the Halstead mastectomy and medical doctor who practiced in the early twentieth century, rarely told his patient she had cancer, though he did often tell her husband [2]. In the 1950s, physicians used words like tumor or growth to avoid using the "C-word" with their patients because it was seen as a stigmatizing disease [3, 4]. There is some question of how far to take the idea that patients suffered in silence for a majority of the twentieth century because of the social stigma of cancer. Historian Barbara Clow persuasively argues that "neither private nor public discourse entirely supports" the assumption that Americans were as reticent to talk about cancer as the term "silence" implies. Regardless, a patient's options for preserving her fertility before cancer treatment or treating her infertility after, even assuming that topic would have been discussed as part of her cancer therapy, would have been far fewer in the not-so-distant past [5, pp. 297–298].

However, this does not mean a woman in 1909 or 1959 would have been without options for medically treating her infertility. While doctors probably did not make a connection between cancer treatment and resultant infertility in 1909 – more on cancer treatment in a moment – if a patient had gone to her gynecologist because of her inability to conceive, there is a possibility that he (and I use the pronoun here on purpose) may have discussed infertility treatment options with her. Physicians, particularly gynecologists, first published their accounts of treating infertility in the mid-nineteenth century, just as gynecologists sought to establish themselves as specialists. As early as 1856, J. Marian

Sims started to treat infertility surgically, specifically incising the cervix to make the opening to the uterus wider. And though he never did so as a first response to infertility, Sims also experimented with artificial insemination with the patient's husband's sperm, though at least one of his peers used donor sperm if the husband's proved lacking [6].

In the seventeenth century, Americans would not have considered seeking medical attention for their inability to conceive; doing so may have been viewed as defying the Lord. But by the late nineteenth century, while women probably did still pray, they also increasingly turned to doctors to help them conceive. By that time many more physicians had joined Sims in operating to restore fertility. Margaret Marsh and Wanda Ronner, in their history of infertility in the United States, found that by the late nineteenth century, and increasingly so by the early twentieth, before annual visits to the gynecologist became commonplace, women from both working-class and middle-class backgrounds, regardless of race, sought infertility treatments from doctors. Women with less means went to clinics where they were often treated for free or reduced costs. Though we do not know the rate of success for these treatments, by going to the doctor seeking assistance for their inability to conceive, women from the middle as well as the working class were indicating that they considered infertility a medically treatable condition by the early twentieth century [6].

By the late nineteenth century and through most of the twentieth century, the medical options available to women included surgery to unblock fallopian tubes, artificial insemination with a husband (or donor's) semen, and "ovarian transplantation" which involved grafting portions of an ovary from a fertile woman into a woman who lost her ovaries from disease. Options in ART increased during the twentieth century. Though John Rock and Miriam Menkin in the 1940s fertilized four human eggs in vitro, and the publication of their achievement fanned the hopes of many women having difficulty conceiving, the first baby born from this technology did not arrive until the late 1970s [6]. By the 1980s, the ART initially chosen by Cathy, IVF, ceased to be experimental; indeed, it had become part of the accepted reproduction landscape. As Lisa Hope Harris described in her history of IVF, cultural conceptions of motherhood, of the family, and of working women shaped IVF, and the technology in turn reshaped social ideas about motherhood, the family, and working women. Twenty years after IVF technology brought forth the first "take-home" babies in the late 1970s and early 1980s, the technology was no longer seen just as a panacea for those unable to conceive. More importantly for its further development, according to Harris, was how the media showed it as a break-through for women who delayed childbirth because they had entered the professional workforce. IVF helped reshape the public's discussion about women's pregnancy options: IVF was not simply a response to women delaying pregnancy, it also enabled women to feel like they could delay pregnancy, argued Harris. Or at least that was how mainstream media represented this technology. IVF and other ART became tools for women (and couples) with the means to pay for them – whether or not they were the ones most in need of such technologies. Harris's account of the history of IVF in the United States reveals the cultural and economic influences on the development of medical technology [7].

Part of the cultural landscape from which IVF blossomed was the very vocal political element uncomfortable with assisted conception and the status of embryos created through medical intervention. In the late 1960s, when assisted reproduction techniques like IVF were still in their gestational stage, the majority of Americans disapproved of attempts to create life through such means, an early indicator of what became a greatly contested medical and cultural discussion on reproductive decision-making. As Harris described, the aversion, even hostility, some Americans felt toward assisted reproduction and the resultant embryos, meant that technology developed largely outside of public purview: federal lobbying by pro-life groups resulted not only in no public funding of the research but also no federal regulation of that research. As a result, ART developed in the private, market-driven world. During the late 1980s, one doctor compared the lack of IVF regulation to the Wild West, saying “It’s kind of like Dodge City before the marshals showed up” [7, p. 311]. IVF remained largely unregulated on a federal level until the passage of The Fertility Clinic Success Rate and Certification Act of 1992, which required all fertility clinics report pregnancy success rates (many of them were advertising enhanced success rates, sometimes deceptively high). At the same time, the Federal Trade Commission began targeting IVF clinics who were padding pregnancy success rates. By the early 1990s, Harris noted, people seeking IVF had access to information about clinics, but these clinics still operated within a marketplace, not a research, environment, and the protections regarding the use of reproductive technologies were largely consumer protections [7]. According to Marsh and Ronner, this left it up to individual clinics and practitioners to decide what technologies and techniques were acceptable, to establish their own guidelines for deciding what successfully treating an infertile couple meant, and to decide whether or not they wanted to follow the practice guidelines of the American Society for Reproductive Medicine. Further, their existence solely within the marketplace also enabled them to establish their own fees based on what the market could bear [6].

Though Cathy speaks decades later, after IVF had become a medically and culturally established technology, her horror of being made infertile because of her cancer treatment touches on the continued importance placed on biological motherhood as a defining characteristic of womanhood. As Cathy told Fertile Hope, “to know that I’ll never give birth, never be brought my baby in my arms as I lay happy and exhausted in a hospital bed, is a source of great pain. . . It is such an isolating feeling. I feel like I’ll never be the same as other women” [1]. Because of her resultant infertility, Cathy expresses great pain at not being like other, presumably “real” women, women who bear children; indeed, she feels “like every last shred of my womanhood has been destroyed” [1]. Here Cathy ties her feelings of being female directly to her fertility, an identity with long historical roots, though the cultural context – and the cultural stress placed on bearing children – shifts. A married woman in the 1950s, for example, experienced the pain of her infertility during a period of strong social pressures to have a child, compared to the 1970s when cultural worries about overpopulation resulted in less social stress placed on bearing children [6]. Though the individual pain would have presumably been as sharp for each woman, the larger cultural response to her infertility would have been different.

The desire to become a mother is rooted in more than societal or historical pressure; the desire is also personal. Like many women, Cathy viewed motherhood as a future role she would experience, and even though it was a vision of her future self, motherhood was a significant part of how she defined her present self as female and as an adult woman. And like many other young women with cancer, the diagnosis of cancer threatened her life and the possibility, and then reality, of infertility eliminated what she always imagined herself as being: a mother. As Cathy told Fertile Hope, “I don’t see how life will ever be the same after this tragedy” [1]. Motherhood has been perhaps the primary role of women throughout American history [6, 8]. It is this role, a role ethicist Hilde Lindemann Nelson would refer to as a “master narrative,” a story that serves “as summaries of socially shared understandings,” that Cathy desires and feels that cancer has taken from her [9, p. 6]. But it is also what is motivating Cathy and her husband to look for other means to parenthood.

The fact that Cathy and her husband are using a reproductive technology and a gestational carrier to become parents is a reflection of the medicalization of infertility. During the late nineteenth and early twentieth centuries, as physicians increasingly claimed the ability to treat infertility, and women increasingly sought out their services to do so, the inability to become pregnant or maintain a pregnancy changed, as Marsh and Ronner argue, “from a social state into a medical condition” [6, pp. 2–3]. Once infertility became a medical condition, many couples changed from finding parenthood through social means, like assisting others raising their children, to finding parenthood through medical treatment [6].

Cathy and her husband’s desire to use a gestational carrier also reminds us of the fluidity of historical and cultural ideas of the means to motherhood. What and how one becomes a mother, the importance placed on physically bearing a baby, and how pregnancy and motherhood is medically, personally, and popularly seen as a part of being female, is not contextually historically constant. Motherhood, as historians Rima Apple and Janet Golden remind us, is neither “a static concept nor is it a homogeneous category” [10, p. xiii]. In Colonial times, for example, fertility was necessary for familial survival, but infertile (white) couples raised children brought forth in a variety of ways: through taking in motherless children, adopting parentless children, or raising children living with them whose parents sent them to work in their household. Belonging to a household, not just biology, defined membership in a family [11]. Because she is exploring an alternative path to becoming a mother, Cathy is part of these more expansive historical maternal roots.

At 35, Cathy was still of child-bearing age (and actively trying to conceive) when she was diagnosed, reflecting the increase in the number of younger people who are today diagnosed with and survive cancer [12]. Her age, and the fact that beneficial treatment was available to her, illustrates the innovations made in cancer research and treatment that were a direct result of the federal government’s investment in medical research. Beginning in the 1930s with the creation of the National Cancer Institute in Bethesda, Maryland, and then following World War II, the United States government intensified the amount of financial support for cancer research as part of the beginnings of a national

medical research policy [13, 14]. Following World War II, the federal government dramatically increased spending on cancer research: in 1947, \$14 million went to fund cancer research, growing to \$110 million in 1961, then nearly doubling to more than \$200 million in 1970 [15]. Since 1971, when President Richard Nixon declared a “war on cancer” and the federal government directed the National Cancer Institute to coordinate research and innovations in the detection, diagnosis, and treatment of cancer, the number of cancer survivors has increased, along with the acceptance that a “C-word” diagnosis did not equal death [12].

Cancer control in the late nineteenth and early twentieth centuries largely revolved around prevention, early detection, and quick intervention.¹ Though some physicians felt looking at the causes of cancer was equally important, by and large, efforts were directed at early detection and treatment. Public education encouraged people to see their doctors as soon as possible if they suspected cancer. In 1913, surgeons founded the American Society for the Control of Cancer to advocate for awareness of early signs of the disease because they believed people came to them too late, having been either unaware of indications of cancer, or unsure of whether the cancer could be cured, or too fearful of what treatment entailed to seek medical attention until the disease had progressed past the point where doctors could effectively treat it [14]. Although radium was beginning to be used to treat cancer in the 1st decade of the twentieth century, treatment largely consisted of surgery until after World War II, when chemotherapy and radiation became part of standard cancer treatment [15, 16]. The stress placed on early detection and treatment dominated cancer control until the 1970s, when greater weight began to again be placed on lifestyle and environmental causes of cancer [14].

The 1970s also saw changes concerning the structure of the doctor–patient relationship. That Cathy discussed her cancer treatment and fertility preservation options with her doctor, and that Cathy recommended anyone else facing cancer treatment and possible infertility “do everything you can to preserve your fertility,” illustrates how patients today expect to be able to discuss their health care options with their provider and actively participate in their treatment options. This ability to “take control” of one’s options for cancer treatment and fertility preservation, as Cathy recommends, rose out of the patients’ rights as well as women’s rights movements in the 1970s. But Cathy’s stress on being active is also part of a longer history, one where American women, through membership in women’s clubs and voluntary associations, participated in cancer awareness programs beginning in the early twentieth century [17, 18]. Moreover, before the 1970s movements, though most patients passively consented to their physicians’ recommendations and doctors controlled most of the interaction with their patients – even, as mentioned above, not telling them of their cancer diagnosis – historian Barron

¹ Both cancer and infertility, as medical conditions, are defined by changes and advancements in theories, research, and treatments; but advances in the medical understanding of infertility or cancer have not themselves initiated increases in demand for treatment. An increase in the use of medical treatments for cancer and ART has more often stemmed from a popular perception that resources existed for the treatment of cancer and infertility – whether or not those resources in fact existed [6, 15]. Changes in the social and cultural understandings of infertility and cancer have played just as prominent a role in their history as changes in medical ones.

Lerner found some patients did take some part in making decisions about their cancer treatment, even challenging their doctors' decisions [3].² Additionally, Cathy's desire to discuss her fertility options also points to her historical link with women who in the past negotiated with their doctors about what infertility treatments they would undergo. In their history of infertility in the United States, Marsh and Ronner found that some patients in the late nineteenth century refused certain treatments or demanded treatments other than what their doctor prescribed, reflecting a certain amount of knowledge on their part about available medical options [6].

As I have briefly touched on here through Cathy's story, medical and non-medical factors contributed to the emergence of oncofertility, and these factors will continue to shape this field. Delving deeper into the history of oncofertility will, I suggest, help us be more sensitive to the medical, social, personal, and ethical issues involved today, and will help us better frame the questions about the field's future use.

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References

1. Survivor Stories: Cathy. <http://www.fertilehope.org/find-support/cancer-survivor-storiesdetails.cfm?SID=611>. Accessed July 9, 2009.
2. Aronowitz RA. *Unnatural history: breast cancer and american society*. Cambridge: Cambridge University Press; 2007.
3. Lerner BH. Beyond informed consent: did cancer patients challenge their physicians in the post-world war II era? *J Hist Med Allied Sci*. 2004; 59:507–21.
4. Lederer SE. *Dark victory: cancer and popular hollywood film*. In: Cantor D, Ed. *Cancer in the twentieth century*. Baltimore: The Johns Hopkins University Press; 2008.
5. Clow B. Who's afraid of Susan Sontag? or, the myths and metaphors of cancer reconsidered. *Soc Hist Med*. 2001; 14:293–312.
6. Marsh M, Ronner W. *The empty cradle: infertility in America from colonial times to the present*. Baltimore: The Johns Hopkins University Press; 1996.
7. Harris LH. *Challenging conception: a clinical and cultural history of in vitro fertilization in the United States [dissertation]*. Ann Arbor: University of Michigan; 2006.
8. Apple RD. *Perfect motherhood: science and childrearing in America*. New Brunswick: Rutgers University Press; 2006.
9. Nelson HL. *Damaged identity, narrative repair*. Ithaca: Cornell University Press; 2001.
10. Apple RD, Golden J. Introduction: mothers, motherhood, and historians. In: *Mothers and motherhood: readings in American history*. Columbus: Ohio State University Press; 1997.
11. May ET. *Barren in the promised land: childless Americans and the pursuit of happiness*. Cambridge: Harvard University Press; 1995.
12. Woodruff TK. The emergence of a new interdisciplinary: oncofertility. In: Woodruff TK, Snyder KA, Eds. *Oncofertility: fertility preservation for cancer survivors*. New York: Springer; 2007.
13. Strickland SP. *Politics, science, and dread disease: a short history of United States medical research policy*. Cambridge: Harvard University Press; 1972.
14. Cantor D. Introduction: cancer control and prevention in the twentieth century. In: Cantor D, Ed. *Cancer in the twentieth century*. Baltimore: The Johns Hopkins University Press; 2008.

² See also Leslie J. Reagan's analysis of the way education regarding cancer was largely directed at women during the first half of the twentieth century [18].

15. Patterson D. *The dread disease: cancer and modern American culture*. Cambridge: Harvard University Press; 1987.
16. Pickstone JV. *Contested cumulations: configurations of cancer treatments through the twentieth century*. In: Cantor D, Ed. *Cancer in the twentieth century*. Baltimore: The Johns Hopkins University Press; 2008.
17. Gardner KE. *Early detection: women, cancer, and awareness campaigns in the twentieth century United States*. Chapel Hill: North Carolina University Press; 2006.
18. Reagan LJ. Engendering the dread disease: women, men, and cancer. *Am J Public Health*. 1997; 87:1779-87.