

Infertility in Women After Cancer

A Dangerous Metaphor, An Important Dialogue

LAURA DURALIJA ROCCA

La perte de la fertilité due au cancer est un problème très important parce qu'il est une perte et un changement qui altèrent la vie des femmes. L'absence du dialogue patient/médecin persiste, car l'infertilité et la ménopause précoce restent un risque toujours présent dans le traitement du cancer. Il reste que tant que les traitements conventionnels et les chirurgies seront tels qu'on les connaît, l'éducation sur le cancer et la fertilité est essentielle afin que les femmes séparent la dangereuse métaphore du sentiment de déficience et du regret que l'infertilité engendre.

Surgery tomorrow. Very nervous.

I didn't have much time to digest this new surgery date, which is ironic, because I am on a two-day pre-op fast and have nothing in my tum to digest. (Though tums always find something from last Wednesday to bring back up as soon as pain meds start.)

Also ironic: I gave up eggs this year, and now I am losing mine. And "synovial" comes from the Latin "synovium," which means "with eggs."

I am pretty mournful about losing these little eggies. I also want to apologize to them for not having frozen a few for a rainy day. I had no idea a thunderstorm was coming.

I'm sorry little guys. I am kicking myself so hard it hurts.

My fertility specialist, Dr. Kind Eyes, says that I can get little donor eggies and still be the mum I wanted to be, just through a different process. He said he'd be honoured to help me do that. Very nice man that Kind Eyes.

I tried everything, though. I Googled, I ran all over the place, I was frantic. There was one experimental possibility, but our beloved government has just passed legislation against it. Thanks.

Then I Googled other things and scared myself. Google can be dangerous. Don't do it.

I just realised something ... Easter is ruined for me. No more Easter candy, please.

—Pre-second-oophorectomy blog post excerpt, October 28, 2008.

Military Attack

I lost my first ovary at the age of 27. At 24, I was diagnosed with synovial sarcoma, a rare soft-tissue cancer, and had had surgeries to excise cancer from my neck, lungs, and, now, my ovary. It seemed a cruel irony. The tumour in my lungs appeared, in a small dark spot on an X-ray film, around the time that I developed an interest in half marathons; the tumour on my left ovary was discovered, after countless—perhaps optimistic—ultrasounds,

right around the time that the notion of motherhood was gradually becoming so much more than just something that other, slightly older women with much more stable bank accounts did.

I had a long-term partner. Thirty was on the horizon. I hadn't given up on my career, but I had decided that I wouldn't have to give up a career or a peripatetic lifestyle or a large, organic garden any more than my partner would. We would be decidedly *hip* parents. We would take our children everywhere. They would become part of our lives, part of our work—scruffy, miniature adults with grass stains. Cancer had shifted my five-year-plan into high gear. Though I felt that, on a professional level, I was about twenty-two, my desire for children was approximately in line with that of a 35-year-old-woman. Cancer reminds us that we are mortal. It also sometimes reminds us that we want little versions of ourselves around, and perhaps sooner rather than later. This is sometimes counter to cancer's plans, however.

"This mass is nine centimeters in diameter," my gynecologist-oncologist told me, after she had examined the final ultrasound report. Her hands were on my knees and she spoke slowly, as one might to an indignant child. "It has literally engulfed your ovary. I'm sorry, but I am going to have to take the whole thing out."

Literally engulfed. I felt, at the time, though I recognize a slight penchant for the dramatic, that my cancer was consuming me in the most dramatic of fashions. It was *attacking* my fertility in a strategic, military surge—one that would soon necessitate an additional counter-attack in the form of chemical defense.

It wasn't long before the remaining ovary had to be excised as well. Prior to that, I'd been given a quick précis on fertility preservation, told that it was expensive and not always successful, and also assured that the metastasis of my cancer to my left ovary was highly unusual, a likely fluke.

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The Nonself

In her revolutionary essay, *Illness as Metaphor*, Susan Sontag lists and deconstructs the metaphors our culture has attached to formerly, tuberculosis, and lately, to cancer. She notes that such associations are, indeed dangerous, as they create stigma and cast undeserved blame upon the patient. Sontag urges us to view cancer as nothing more than a disease—one that should be liberated from such mythic affiliations. One of the metaphors often associated with the disease which Sontag demystifies is that of cancer as “punishment” for a life not fully-lived, and, in extension of this, cancer cells as an “invasion” rapidly multiplying as representation of the “nonself”:

As TB was represented as the spiritualizing of consciousness, cancer is understood as the overwhelming or obliterating of consciousness (by a mindless It). In TB, you are eating yourself up, being refined, getting down to the core, the real you. In cancer, non-intelligent (“primitive,” “embryonic,” “atavistic”) cells are multiplying, and you are being replaced by the non-you. Immunologists class the body's cancer cells as “nonslf.” (67)

This “punishment” for a woman's stagnant life or suppression of emotions and “invasion” of the self by the nonslf has often been represented in literature in the form of a tumour after the long absence of a pregnancy. Sontag points to the example of W. H. Auden's ballad, “Miss Gee,” wherein the central character, a lonely, post-menopausal woman who wears “clothes buttoned up to her

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neck” is consumed by a sarcoma so advanced that she becomes a source of study and the doctors and residents examining her body after her death marvel at the size of it. Miss Gee is a reclusive spinster who has, from what we may gather, lived an unromantic life, and in the end is much like the Cornish wreck to which Auden alludes: one of many nameless vessels that no longer serves a purpose, but may be scavenged one last time for anything of value. She is described as flat-chested, with thin-lips and a slightly squinty eye. She is unmarried and has no children. There is nothing “feminine” about Miss Gee at all, and the Doctor's general remarks in the poem make us wonder if this “invasion” of cancer in Miss Gee's body is meant to be viewed as invasion of the nonslf in the absence of pregnancy:

Doctor Thomas sat over his

dinner,/ Though his wife was waiting to ring;/ Rolling his bread into pellets,/ Said: “Cancer's a funny thing.

“Nobody knows what the cause is,/ Though some pretend they do;/ It's like some hidden assassin/ Waiting to strike at you.

“Childless women get it,/ And men when they retire;/ It's as if there had to be some outlet/ For their foiled creative fire.” (57-58)

Similarly, in Margaret Laurence's novel, *A Jest of God*, Rachel Cameron experiences a false pregnancy, which turns out to be a (in this case, benign) tumour. The character of Rachel believes herself to be pregnant, but in fact, it is a demonic pregnancy: she has a large fibroid growing on her uterus. Upon the Doctor's surprising diagnosis, Rachel muses over the painful irony of her situation:

Doctor Raven puts a hand on my shoulder. His face is anxious. He is anxious about me. Anxious in case I should be too concerned over the nature of the thing in me, the growth, the non-life. How can a non-life be a growth? But it is. How strange. There are two kinds. One is called malignant. The other is called benign. That's what he said. Benign. (187)

Benign as it is, Rachel's tumour may be viewed as a symbol in *A Jest of God*; it is a metaphor for the stagnant life that she has lived. Rachel, still a virgin, living at her mother's house and stuck in her hometown of Manawaka, was like a child in a woman's body before her tumour. She is released into adulthood when her tumour is excised. As she awakens from her surgery, she says “I am the mother now” (191). The non-invasive nature of her tumour liberates her from the nonslf.



Top: Ifosfomide, one of the two intravenously-administered drugs involved in sarcoma protocol. Bottom: Laura with her chemotherapy nurse, December 2008.

Reclaiming the Self After Cancer

In Ways of Seeing, John Berger (7) argues that “the relationship between what we see and what

we know is never settled.” Berger was referring to visual art—specifically, to oil painting—but let me regardless take that completely out of context and apply

it to a woman’s self image during chemotherapy. I have heard and repeated to myself such things as “cancer cannot take away your beauty” many times ... I have been tempted to write it on my bathroom mirror in bright, red lipstick. I want to believe it.

—Blog post excerpt, January 29, 2009.

After cancer, many women have difficulty in liberating themselves from metaphors, as cancer is a disease that can drastically change a woman’s relationship with her body. On top of the pain and loss associated with infertility, which may be a result of a gynecological surgery or a round of chemotherapy, it is easy to feel less than feminine when one is bald, underweight, in the throes of menopause before her time, post-mastectomy, and sans eyelashes and eyebrows. This often caused me to rethink my notions of age and gender, respectively. Certainly, it is traumatic for a woman to be facing menopause before she is even 30, but if the loss of my ovaries made me feel like “less of a woman,” how less feminine would I consider a woman my own mother’s age, who had gone through natural menopause? Was it that I felt I had less of a purpose, now that I could no longer produce my own offspring?

Although I felt certain in my desire to have children, the truth was that, regardless, the culture of motherhood is assumed and implied; it is something that is forced upon us early on, from the very first time a flax-haired doll with a painted-on smile is placed in our arms. It is reinforced with comments, delivered with winks and nods, such as, “You’ll understand when you’re a mother one day,” and in repeated reminders that the “clock is ticking.” It is reinforced by attaching the word “childless” in hushed tones, as a footnote to the description of a couple that lives down the street. It is reinforced in our popular culture’s obsession with “baby bumps” and “celebrity baby watching.” And an

infertile cancer patient is reminded of it, each time she awaits an X-ray or CT scan, by the repeated question “Any chance you might be pregnant?”

These are assumptions and associations that are quite seldom imposed upon our male counterparts.

The loss of fertility due to cancer is a very important issue, but it is a difficult loss for many women, and not solely for heterosexual women who wish to have children. The loss of a woman’s ovaries, particularly at a young age, has a profound effect on her body: not only is the body depleted of its natural estrogen levels, and the woman sent into early menopause, but it is also a loss of an organ which our society—wrongfully—uses in the construction of gender. It is assumed that all premenopausal women menstruate; it is expected that most women will attempt to procreate—and even if they have no plans to do so, they nonetheless have that ability. My partner had often told me about a woman he had known growing up who had been diagnosed with ovarian cancer (well before menopause). She was not in a committed relationship, nor did she have any foreseeable plans to have children; nonetheless, the radical hysterectomy she endured as a result of her cancer’s metastasis left her feeling devastated over the permanent loss of her fertility. Though she could not explain it, she felt as though her identity as a woman had been shaken.

While the loss of fertility remains a very emotional issue for many women, the preservation of fertility is an issue that, unfortunately, remains rather low on the list of priorities for oncologists. I recall, upon discussion of my fourth recurrence, the response that my oncologist gave me when I asked him if he had any theories behind the causes of my highly-recurring cancer: “I wish that I could say, but I’m not in the business of preventing cancer; I’m only in the business of treating it.” His answer, though honest and forthright, left a resounding feeling of dread deep in

the pit of my stomach, and I suddenly felt very alone with my cancer. There is no time for ancillary care in oncology.

It is for this reason that fertility preservation is a conversation topic between patient and oncologist that is often either brushed aside or barely mentioned.

It was a conversation that happened all-too-late for Marty, a young woman living in Sodoltna, Alaska who responded to my call for personal thoughts and stories and wrote to me via Planet Cancer (a social network much like Facebook for young adult cancer patients of the eighteen and forty demographic). Marty was diagnosed with metastatic breast cancer in 2008. It was assumed by her oncologists that, given the nature of her illness and the fact that she had one biological child and two stepchildren already, it was not imperative to inform her that her treatment would render her infertile, until the treatment was already in process:

I met my oncologist on a Monday, and had all my scans set up for the next day. All of the tests confirmed that I had breast cancer that had spread to my bones, and I had broken my hip because of the weakened bones. It was decided that I needed an emergency hip replacement. I was admitted to the hospital [on] Wednesday, had my hip replaced [on] Thursday, and was told that I would have to have some radiation treatments. There had not been any discussion of fertility at this point. I didn't know to ask about fertility. When my radiation oncologist came to my hospital room to talk to me about starting treatment. I was told that my tumours were estrogen-positive, so when the radiation oncologist was talking to me about treatment, he said that he had looked at my scans and there was no way to block my ovaries out of the field. He told me that I would “accidentally” be sent into

menopause, but [that] it was a good thing, because that [was also the] goal of the other treatments; we would just [be able to] do it a lot faster with the radiation. This news came to me less than a week after finding out that I had cancer. I was never told that there were any other options. I was told that this was going to happen accidentally, but [that] I should be happy about it. It was not until I had already had three or four radiation treatments to my pelvis that anyone talked to me about whether or not I had thought about my fertility options. I was told too late that I could have looked into freezing my eggs. I have not had a period since February 2008. I am post-menopausal. I was never told that I had options until it was too late. The way that I was told that I would be sent into menopause was by a doctor I had just met, while [I was] lying in a hospital bed, trying to recover from a hip replacement. He did not offer any options for me, and he seemed happy about it. I am lucky enough that I got married young, and had a child then, but I have had to explain to my son why he will never get to have a little sister (he really would like a little sister). I think that male doctors should really be told that any talk of killing ovaries should be done carefully, and should never be referred to as [a positive thing] the first time that it is brought up. I was not aware that infertility was something that I needed to worry about. Things happened very fast for me in the beginning ... I barely had time to catch my breath, so there definitely was not time to make an informed decision about fertility. I was told that because my cancer was [estrogen- and progesterone] positive [that] menopause was the ideal treatment. There was never any discussion about it.

For Tara of London, Ontario (another young woman in her early thirties who responded and wrote to me via Planet Cancer) the loss of her fertility was less of an emotional issue, but the manner in which it was mentioned—or rather, not mentioned—to her by her oncologists, was a source of anger and frustration: “My boyfriend and I both agreed long ago [that] we didn’t want kids,” she writes. “Since I didn’t want kids,” she continues, “that’s okay. It’s the fact that I was never told that is a problem.” She adds that the loss of her fertility had not affected her sense of self or her identity as a woman, but that “it’s the treatment damage and menopause that make me feel [useless] . . . I basically knew that I would become [infertile] from the treatments, but the doctors never actually *told* me this. I had to find out myself by doing my own research.” Reviewers suggestion: these problematic constructions (as above) around infertility [according to what is highlighted above, do you not mean “the problematic constructions around” *menopause?*] need to be addressed as well

Both women agree that more dialogue between oncologist and patient is needed, upon any cancer diagnosis. Yet the absence of this dialogue persists, and infertility and early menopause in cancer patients remains a common, often devastating problem. It is a rather dire situation, as the window for fertility preservation in women with cancer remains quite small; moreover, unlike in the case of men with cancer, fertility preservation after diagnosis is much more complicated, invasive, expensive—and often not possible. If cancer is involved in one or both ovaries, stimulation of the ovary, in the endeavour of extracting eggs for freezing, is quite dangerous, and can accelerate or further spread the cancer; moreover, implantation via egg donation (following cancer treatment) carries with it some legal complications, and it is far more difficult to obtain an egg donor than it is to obtain a sperm donor in Canada.

AD (After Diagnosis) is pretty bad. I feel like the Sabine Woman statue outside of the Uffizi (only instead of marble Adonises, I am being engorged by ugly, green little synovial cell monsters who refused to die). It is violently robbing me of my fertility, my freedom for the next six months, and that last shred of naive optimism I cherished so very much . . . I can count on my oncologists to rid my body of these physical malignancies the best they can, but one cannot ignore the emotional malignancies cancer creates.

—Blog post excerpt, Sunday, October 26, 2008.

Perhaps, as cancer research advances and targeted therapies and immunotherapy become viable treatment for all cancers, the urgent need for this discussion between patient and doctor will disappear. Until then, however, more education on the topic of cancer-related infertility is essential; only then will women be liberated from the dangerous metaphors, the feelings of inadequacy, and the profound sense of regret often resulting from infertility. It is wrong to assume that all women value functioning ovaries solely in order to procreate. It is also wrong, however, *not* to assume that every woman—regardless of age, class, sexual orientation, religion, or race—has a firm right of entitlement to that very discussion.

Laura Duralija Rocca holds a BA Honours in both Drama and English Literature from Queen’s University, and an MA in Drama from the University of Toronto. A five-time survivor of a rare form of soft-tissue cancer, she is the founder and co-producer of Upstaging Cancer, an annual arts festival featuring theatre, music, and dance, in support of cancer research. A theatre artist by trade, she is an actor and the Artistic Producer of DreamNorth, a theatre company dedicated to touring the works of William Shakespeare to Canada’s North. In her spare time, she blogs about cancer for Best Health

Canada Magazine, and is studying towards becoming a Registered Holistic Nutritionist. Laura divides her time between Nelson, BC, and Toronto, Ontario. She lives with her partner Robin, and their three-year-old Sheltie/Golden Retriever cross, Auden. In spite of cancer, Robin and Laura hope one day to expand their family, in whichever way they can.

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Irene Gust lives and works in Tübingen /Germany. She studied cultural ceramics and fine drawing at the FKN, Nürtingen. She has been a member of administration staff at the Eberhard-Karls-University, Tübingen since 2000. In 2004, she was diagnosed and treated for cervical cancer. In 2006, together with Britta Rochier, she founded the self-help group “Treffpunkt Krebs” (www.treffpunkt Krebs.de), a non-profit, autonomous self-help organization for women living with cancer, which promotes critical discussion about health education, the pharmaceutical industry, and the impact of environmental degradation on women’s health.