

Cancer, Meaning-Making and Hope: The Treatment Dedication Project
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This essay provides a commentary on the articles by Robinson et al and Gilbar in the form of a personal narrative. The author writes Part One in a voice that was adopted and maintained for several weeks after her third diagnosis with cancer, after which the frustrations of medical complications stopped this voice cold. The voice uses wry humor to convey rage, grief and acceptance. Part Two, written in the author's usual voice, about the period three to six months post-diagnosis, describes the author's ultimately successful struggle to connect the necessary work of a cancer patient with the author's work in the world. It is in the integration of these two worlds that the author finds meaning and is able to generate ideas about the nature of hope.

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Part One

My mother died the day a review of her fourth novel appeared in *The New York Times*. Compared to that standard, the fact that I was diagnosed with cancer for the third time the week I was to have gone on a book tour was hardly catastrophic. I did scream into the phone, though, as my husband, Hilary, told me what the oncologist had told him moments before. I screamed long after I hung up the phone, terrifying my three dear friends who gamely followed me from room to room while I paced frantically.

I have gotten all three diagnoses over the phone, which I think should be outlawed as a practice. The first was actually over my answering machine. My surgeon, who has now operated on me 11 times in the past 25 years, told me that my husband and I should come into his office immediately. If that isn't a tip off, what is? I told him later, "Clinton, you have left messages on my answering machine three other times. They all said, 'Everything's fine.' Didn't you think I would figure it out?" I didn't have to be more persuasive. Among the many skills he has, listening is high on the list.

The second time was oddly corrective for the first. I had felt a pea-sized lump and gone to see the surgeon. He had felt it and agreed it felt

concerning. It was so small, I decided to have the surgical biopsy under local anesthesia. “Tell me how it looks,” I had said. “Just be direct.” “Bad,” he had said during the procedure. “Thanks, I had replied. So when he reached me by phone and said, “We were both right,” I accepted the compliment before I wept.

This third time I screamed for a long time. It had been ten years since the previous diagnosis. During that time, I had suffered pain most days due to problems related to the previous two rounds of treatment. It made no sense to me that I should have yet another breast cancer...and a new kind at that. With no family history, no positive genes, it was surreal, almost embarrassing. How many times was I going to ask these same friends to accompany me through treatment? We were 16 years older. Everybody, by now, had other friends with cancer. Friends were dying. Needing help a third time was ...well, selfish. Like taking more than my share of the social support resources in the community. I had gotten plenty of help when I had little children and the sound of my vomiting every 10 minutes for 15 hours scared the pants off them. Friends had taken them overnight so I could puke without trying to keep my gagging sounds down. Five years later, with teen-agers in the house, friends had come through with tickets to the Red Sox and gourmet pizza.

Now these three dear women were in for the night with us. We were waiting for “data.” The oncologist was going to read the slides

himself later that evening and let us know what he thought. We knew my surgeon would call.

There had been a mistake, which we all knew would have to be addressed. I had felt something suspicious in my remaining breast in March. My oncologist had examined me and sent me for an ultrasound. The breast radiographer had found nothing suspicious. Three months later, still feeling something odd, I had returned. This time the breast radiographer had been more emphatic. Not only was there nothing there to worry about – despite a palpable mass that she, Hilary and I could feel – but I was scolded and told to “stop examining yourself!” I had, and now the “nothing” was four times the size it had been when I had first brought it to my doctor’s attention.

Hilary came home. He and I went off by ourselves for a while. We came back to the den. My friends told me that they had looked into our refrigerator and deemed it impossible to create dinner for five with its contents. A shopping had to be done; a team would head out to the whole foods market; did we have any requests. I told them what they already knew: I wouldn’t be eating.

I don’t eat or sleep for weeks after I get a cancer diagnosis. And then I do. I loose 10 pounds, which I cannot afford. I look terrible right when people are most worried I am going to die and then I laboriously gain back weight and no one is jealous of how easy it is for me to lose, or

hard it is to gain, because they would have to be nuts, right, to be jealous of anything that happens to my body? Everyone is just sympathetic.

This is an advantage of having cancer three times. Friends and family know the drill. They know I won't eat or sleep; that nothing they can say or do will help; and that eventually my body will plug back into its normal routines. The third time there is no unnecessary expenditure of energy on matters that will self correct.

Those that won't are another matter. We are all anxious about what the doctors will see under the microscope. How aggressive are these suckers this time? Plus they are different suckers than the last two times. Hilary has to go on the computer and do a Medline search to learn all about them. I usually do my own Medline search, but I am not going to be able to read for about four weeks. We also know this. I, who devour two newspapers before 6 AM every day, who read 1200 articles or books in one year for the book she should have been going on tour for, will be unable to read even *People* magazine. Again, no one bats an eyelid when Hilary comes downstairs with a drawing and an explanation for someone with the literacy level of a third grader.

They eat. I watch. The phone rings. Since I am the only one without my mouth, I answer the phone, which I will not do in the evening for the next 6 months since I will be too worn out at night to talk to anyone on the phone.

It is my surgeon. Hilary and I remove ourselves for “privacy,” which is ludicrous since we will be providing a verbatim account of what has been said. Clinton is fabulous. As always. But, when you think of it, you don’t really want to know that about your surgeon. For instance, he and I have had surgeries delayed and he has sat in his scrubs in the holding area with me – not in the doctor’s lounge with his chums -- and I have cried that I only want to see my children grow to adulthood, which is a) what any good parent would say and b) not exactly relevant before a mastectomy -- and he has stayed there, with that cheesy little gauze cap on his hair when, really, he could be reading *The Wall Street Journal* and kicking back in the lounge.

He cuts to the chase. I think we can handle this. His “we” is not the royal one, it is the three of us. He gives us a lot of information and Hilary and I get off the phone feeling like, yes, we can handle this. There are treatment decisions to be made, but we are in the ballgame. That is, there is a ballgame called life and this tumor is going to let us have a lot of innings.

We join our friends, who stop their conversation and look at us expectantly. Looking at us, their soft, wrinkled brows turn from anxious solicitude to puzzlement. We look like we have just been told I don’t have cancer. But we haven’t. We’ve been told we have a very good chance and that our doctor is in it with us. That produces enormous relief.

I smile and joke a little. Hilary digs in to his cold food. The phone rings. It is my oncologist. Again, we rush into another room and huddle together each with an ear to the phone extension. This conversation takes twice as long and we say half as much. The phone feels heavy as we speak and it is only after we hang up that I realize it is I, not the phone, that feel heavy.

It makes a difference that we know both men so well. “Damn,” I say to Hilary. “He has just told us essentially the same information and I want to jump off a cliff. He makes me feel so worried I can’t stand it. Why does he always have to hang crepe? It isn’t even what he says; it’s his tone, that super careful, ‘I just have to be totally honest with you’ style of his. It makes me want to jump out of my skin.”

“Do you want to change doctors?” Hilary asks.

“No. I love him. I think he’s wonderful. It’s just I have to use three grains of salt to manage everything he says in the beginning. He gets more upbeat later. Plus, he’s on email with me.”

So, more surgeries. The second one does not heal and creates a small reservoir in my armpit that will not drain. I learn a new word: seroma. A pretty word and in fact the lymph that exudes from it is gorgeous, a bright sunflower yellow. The problem is that I leak through bandages every 20 minutes or so and that doesn’t stop for 5 weeks.

I’ll spare you the details of my life as it becomes lived in 20-minute intervals, laundry stacks you wouldn’t believe, surgical corrections

and finally, swaddling with ace bandages that only someone else can get me into and out of. Needless to say, I am not going to work.

Part Two

That is about the time that my mood shifted from upbeat and wry to slow and quiet. I know because I am a writer and the pieces I wrote during that time are all in the tone of voice of the pages you have just read. The sensory detail reveals that the writer is, I am, in acute shock. Then my writing stops.

Treatment planning was difficult and my best chance of survival did not coincide with our desired option. Instead of a mastectomy, I headed back for radiation, which had badly screwed me up the last time.

During the treatment planning phase, I wrote to the breast radiologist requesting a meeting to understand what her clinical reasoning had been. I pointed out that 30% of my kind of cancer cannot be visualized by ultrasound. I never heard from her.

The book I had published two months before and which “sailed without me” is about witnessing violence and violation and turning that passive, sometimes inadvertent witnessing into effective action of some kind. Taking my own approach, I followed up by writing to the head of her department, presenting what had happened and urging him to use this as an occasion to “turn this unfortunate episode into constructive learning. Naturally, if I were to have my say, I would most wish an outcome in

which no woman is ever told not to examine herself when there is a lump.” Ultimately, I had some satisfaction in my correspondence with the head of her department.

On December 1, International AIDS Day, I was in the audience for a Grand Rounds I was supposed to have helped prepare, but had not. Part of my work involves consulting to colleagues in South Africa who are deeply involved with the AIDS pandemic. I had hoped to contribute some insights from their work. Multiple emails had appeared in my inbox the previous weeks, each one making me feel more and more diminished as I had to face that while my husband and local colleagues were organizing statistics and slides about the pandemic, I was juggling appointments and bandages.

Hilary started the Grand Rounds playing an excerpt of Robert F. Kennedy’s historic speech in Cape Town, South Africa, in 1966, during the height of Apartheid and our Civil Rights era. Kennedy’s opening is stunning:

I came here because of my deep interest and affection for a land...which once imported slaves and now must struggle to wipe out the last traces of that former bondage...I refer, of course, to the United States of America.

Kennedy created a reversal; there, he was talking about here. I realized that I, too, could reach out here and touch others there. It was the proverbial light bulb going off: an epiphany. True, my work was lying in the bowels of a hospital getting zapped by electron particles. But,

strapped to the table, as stripped down as one can get, I still had something to offer others: those very same particles that were entering my body and, hopefully, giving me a chance for a long and productive life. How different from the people my South African colleagues were helping, who weren't being given state-of-the-art treatment. I saw many connections and a path toward action.

After radiation that day, my eighth session, I sent off emails to four of my closest South African colleagues.

As you know I am undertaking radiation treatment. While there are discomforts, I am mindful of how fortunate I am to be able to receive treatment. I am dedicating my next session to the four of you for all that you do for those who suffer with AIDS and for those families, caretakers and communities that suffer as well. In deep gratitude for all that you do.

Sending off the email, I felt back in my life for the first time in months. A few hours later, I devised a plan. Each day I would dedicate my radiation treatment to a person or a cause whose work in relation to violence I wished to honor. I hoped that the knowledge that someone cared enough about the work they were doing to dedicate their treatment to them would encourage them in the daily challenges they faced.

For the next twenty-five days of my treatment I researched people and organizations to whom I would write letters, and worked on how those letters could truly witness their work. I labored over each letter, explaining why their work moved me to link them to my daily work of being radiated. I wrote to the Medical Foundation for the Care of Victims of Torture and a reporter based in Iraq. I sent the letters off with no

expectation that I would hear back, although I did hear -- and was touched when I did -- from over half of my dedicatees. Writing the letters helped me focus on one aspect of global violence each day and believe that I was contributing to the effort to make a positive difference.

Dedicating my treatments made the radiation sessions themselves tolerable. First, it resolved the contradiction of dreading the pain of radiation when I know what a privilege it is to have treatment at all. Second, I was doing my work, on and off the table, by transforming my private pain into an opportunity to recognize others' efforts to transform violence. Third, the pain felt different. I was using my body to absorb rays that I could then send out beneficently to others. Finally, in focusing so intently on the people, organizations, and causes I had chosen to honor, I felt connected to them, defeating the feeling of isolation that grinds down people living with cancer.

Months after treatment ended, I turned my private experience of treatment dedication into the Treatment Dedication Project. I wrote two guides, one for those undergoing treatment and one for those who wish to facilitate the dedications. Many people who receive treatment for cancer would love to do something like this, but do not have the energy or focus to take it on themselves. Although I believe I would have had a keen interest myself sixteen years ago, my first time around, I doubt I would have had the time or personal resources to do it alone while I was

managing work and two young children. With help, I might have been able to participate.

A wonderful graphic artist, Natalie Zammito, volunteered to design the Guides, and a local foundation underwrote the cost of producing the guides (<http://www.witnessingproject.org/treatedd.html>) in memory of Peter B Natchez, who died of cancer in 1981.

I have written a lot about hope (Weingarten, 2000, 2004, in press). Hope may be a feeling, but expecting people who are sick and scared to feel hopeful may be expecting too much. I prefer to think of hope as the responsibility of the community. Hope is something we do together. The latest research makes it clear that hope is essential to health (for a review see Groopman, 2004). This makes it even more crucial that hope be available to all, not just those few robust people who can summon hope – or cockeyed optimism – under the most challenging circumstances.

I believe that hope *can* be made available to all, because we can do hope together. Hope is a verb, not a noun. Hope is helping people feel connected when cancer makes people feel isolated. Hope is resisting indifference to the plight of those who are sick and diminished. Hope is doing what one can for others.

When I feel really crummy, I drive particularly politely. Some days it feels like the most I can contribute to the world is letting someone who is out of line, literally and metaphorically, enter the stream of traffic ahead of me. During cancer treatments, I have felt a pale version of

myself. I have longed, but not known how, to make my daily life – going to the hospital, waiting, getting one test after another, being zapped, cut or poisoned – have meaning in the larger context of the world about which I care so deeply. Dedicating my treatments and The Treatment Dedication Project have done just that for me, and now for others who tell me that it helps them do hope.

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