

Running Head: PUNCTUATING ILLNESS

**Punctuating Illness:  
A History/Herstory of Breast Cancer**

Eric Paul Engel & Shelba Engel

University of South Florida

Abstract

Blending ethnography and poetry, this co-authored narrative explores a punctuation of illness in three episodes: “History” (a son’s reflections on going wig shopping with his mother), “Herstory” (a mother’s reflections on diagnosis day), and “Ourstory” (shared reflections on health, illness, and relationships). The first episodic memoir stands in dialogical juxtaposition to the second, punctuating the day breast cancer first became “real” in two people’s lives, with the third story commenting on an episode of research, relationships, and reflexivity. In form and format, our research goal has been to provide a contextually-rich narrative to facilitate conversations about cancer and communication.

*Keywords:* Narrative, Cancer, Relationships, Ethnography, Poetry

*Author’s Note:* This paper was accepted for presentation at the Fifth Annual International Congress of Qualitative Inquiry in Urbana Champaign, Illinois (23 May 2009). It was included in a panel titled “Writing the Personal as a Method of Inquiry” chaired by Manijeh Badiee. The author is indebted to colleague David Lee for presenting in the author’s absence.

## A History of Breast Cancer: A Son's Story

The bell just above the doorway rang as we left the warmth of the afternoon sun. I held the door as my mom, Robin (my sister), and Jowita (my significant other) entered the long, thin store. Retrieving a grey cloth case from my front left jeans' pocket, I removed my sunglasses and tucked them safely away.

I was struck by the color of the walls—a pale lime green with white trim. The shade seemed sickly. “An awkward choice for a cancer store?” I thought to myself. Next, I noticed several small round tables off to the left draped in white cloth, stacked high with knickknacks and trinkets. There were bookmarks and paperweights. Small but ornate picture frames for family photos (ideal for the desk at work). Greeting cards with messages like “Get Well Soon!” and “Hang In There!” stood propped open next to small blank books with elaborate covers (ideal for purging hopes and dreams, for putting pen to paper in a therapeutic act). Mixed scarves spilled from a basket on one table. Some were woven dense from thick black yarns for warmth. Others were delicately ethereal, threads of silver interlaced with wisps of red and blue, glittering and alive. They were mostly little items, perfect as gifts.

Off to the right was a small bulkhead with a cash register. On the counter, just in front of and above the cash register, I noticed a rack with tiny inspirational books of poetry and prose. At two inches tall, the books' diminutive design and artistic aesthetic commanded my attention. Inside, I found simple words, reminders of hope and happiness. Beside them on the counter were a mix of small, “last minute purchase” items like gum, mints, and finger puppets. And more bookmarks. It made sense. When I'm not feeling well, curling up with a good book can make convalescence

acceptable (and I wouldn't want to lose my place if I happen to be struck with the urge to nap).

About ten feet beyond the checkout counter, there was a wall filled with mannequin heads and wigs covering roughly half the width of the store (from right to left). It helped to separate the front of the store from the "hair salon" in the middle of the store, creating a semi-private space for women who wanted to have their heads shaved on site by women who'd themselves experienced hair loss as a result of chemotherapy.

"Some women are quite self-conscious after chemotherapy," the attendant later explained to my mom. "We have a couple of private booths in the corner there for hair appointments, but it's generally considered better to be out about it. It's healthier." At the back and off to the right of the changing area, a non-descript black door led to the employees' section in the rear of the store.

When we'd first arrived, we'd made our way to the middle of the store where we met the attendant who was already busy helping another customer try on several wigs. Catching a glimpse of the woman's pale bald head as she changed wigs, I felt I had somehow overstepped an invisible boundary (the "semi-private" part of the space) and so quickly retreated to the front of the store where Jowita joined me. Moments later my mom and Robin emerged with the sales attendant.

Mom was relatively quick about the matter. She had yet to begin chemotherapy, so she put a cap over her hair. Jowita was familiar with the process (having worn a wig or two in her day), so she offered some assistance. Once the hair was snugly in place, Mom retrieved the first of her selections from the attendant. It was a dark brown

number, long with a moderate wave. I remember thinking how strange it looked. I remember how strange I felt, as if I were judging wigs for a performance in which my mom would play the lead role.

“What do ya’ think?” She asked a bit too enthusiastically, laughing at her own profile in the mirror. Taking life in stride, Mom played the lead, camping up the moment. Since the long wig didn’t work for her, she next asked the attendant for a short blonde wig. When the attendant returned with a short blonde mullet, Jowita and I couldn’t help ourselves. I made a reference to Ziggy Stardust; Jowita brilliantly noted the obvious, “Nice mullet!”

“Hey!” she barked, fighting back the laughter. “I can pull it off if I want to. I can make it work.” At this, we all burst out laughing. I noticed what I thought were tears welling up in my sister’s eyes. As she laughed, she seemed relieved somehow. My mom was upbeat about the prospect given the circumstances, accepting the inevitable with a laugh and a smile.

Jowita and I followed my mom’s emotional lead. For me, it was a conscious decision. For Jowita, it was just natural. She saw my mom laughing, and she laughed with her. As my mom tried on wigs, Jowita and I tried on hats and scarves in the vicinity.

While Jowita and I were goofing off, my mom and Robin talked to the attendant. She explained how all of the women who worked at the store were breast cancer survivors. Pointing to a little girl playing off to the side just behind the front counter, the woman explained how she’d been pregnant when they’d first diagnosed her. I remember thinking how Mom seemed at ease listening to a fellow traveler tell her tale.

Out of the corner of my eye, I noticed a woman emerging from the changing area. It was the same woman who'd been in the back trying on wigs when we'd first entered the store. Slowly, she moved past us now and made her way to the checkout counter to pay for her purchase. A dark blue fleece cap now covered her pale forehead. She was watching Jowita, and she was smiling. Oblivious to the audience and ever the ballerina, Jowita giggled and pirouetted, modeling first one and then another hat.

My mom tried on a number of wigs that day, but she didn't dawdle in her decision. Less than an hour later, we headed back out the door and off to lunch. I remember my mom was smiling, new purchase in hand. I reached into my pocket for my sunglasses as the bell rang above the front door, Jowita bounding out onto the sidewalk and into the afternoon sun.

Two years later, I asked my mom about that trip wig shopping. I explained that I was writing a paper for one of my Ph.D. courses, and how this memory really stood out.

"Really?" She laughed, "I can barely remember it."

## A Herstory of Breast Cancer: A Mother's Story

One day you get up,  
and you go to work,  
and it's humdrum.

And you know you dread  
cause you've got to get  
that crappy mammogram  
which every female hates.  
You just hate it. But 'cha gotta do it.

So you have an ordinary day.  
You rush through this. You rush through that.  
You give up lunch so you can go there and have it.

You get there and you have it.  
You wait in line with all these people  
with this little crappy robe that opens up in the front and ties.  
And you can't tie it cause half the ties are broke.  
You wonder where they got these gowns  
cause they don't fit anybody.  
They're horrible. They're all different colors.

They have these little booths with material that comes down that won't shut,  
and you take your clothes off and fold 'em up and leave 'em in there,  
and you come out and you sit there and you wait with all these people.

You go in this room, have your mammogram taken.  
You go back, you sit,  
you wait, you wait, you wait,  
and pretty soon they'll come out and they'll say,

“Ms. X, you’re o.k., you’re free to go.”

And they come out and they tell everybody that,  
and they come out, and they say,

“Ms. X, we need to take another...

there was something...

No... we need to take another mammogram.”

And for the first time in my life I thought,

“Oh shit. I’m in trouble.”

So then I go back to take another mammogram.

And then she comes, and I’m thinking,

“Well, maybe I moved,”

cause you can mess ‘em up,

or they can see a spot and it can be nothing.

And then they come out and tell me,

“I’d like to... could you just hold on a minute?

I’ve got to go get Dr. So-&-So.

She’s head of radiology here.

I need her to talk to you.”

Well shit!

They’d just as well have said,

“YOU HAVE A SPOT!

Stay right here.”

And I told them, “No!”

I did not want to talk to her.

That, “Thank you very much,

but send the mammogram through the normal channels”

(like they normally did.)

I would talk to my doctor.

I don't want this cracky-ass person that had...

...didn't know me from Adam,

telling me I had cancer.

At that moment, I knew it.

So... that's how that happened.

And she did not come in and talk to me.

She came in and asked me if I was sure

I did not want her to talk to me,

and I told her I didn't stutter.

I was very sure...

God. I'd forgotten all about that...

So I left there and went back to work

knowing I had cancer.

Not knowing the extent,

but knowing I had it.

### Ourstory of Breast Cancer: A Mother/Son Story

In the fall of 2004, my mom was diagnosed with breast cancer during a routine mammogram. At the time, she was living in North Carolina, and I was living out of state. As such, I wasn't able to be there with her during most of the experience. Jowita and I did, however, visit several times. The doctor had told my mom she'd likely lose all of her hair, so during one of our early visits, just before she began chemotherapy, four of us went wig shopping—my mom, my sister, my life partner, and my self.

Two years later, as part of a "Narrative Inquiry" course in a Ph.D. program, I was assigned to write a personal narrative—an episodic memoir. The decision to write about my mom's cancer was inspired by a presentation I'd given earlier in the semester in which I'd first mentioned her illness. At the time, I became acutely aware of how little I knew about her experience. Having recently read illness and grief narratives by Arthur Frank (1995), Richard Zaner (2004), Robert Coles (1989), Oliver Sacks (1991), Anatole Broyard (1992), and Carolyn Ellis (1993), my curiosity was piqued. I'd become acutely aware of how quickly life can change and how fragile health really is. The readings brought me to tears on more than one occasion, and in doing so I had to face painful emotions. When I thought about my own mother's story and how little I knew, I felt somehow guilty. I felt like I wasn't there for her. I wanted to hear my mom's telling of *her* cancer tale, share in *her* storied memories. I realized how an episode in my life (an assignment for a course) allowed for a series of intimate conversations with my mom (an episode in our shared lives) about living with cancer (an episode in her life).

After postponing for several weeks, I finally called my mom. Hesitatingly, I explained my project and asked if I could interview her. To my surprise, she agreed. I

say “to my surprise” because I really hadn’t expected her to say yes. Our family tends to be tight-lipped about certain things. I imagine many families are. Feelings were rarely a topic of dinner conversation at our family table. On five different occasions, we spent thirty minutes to an hour talking. “A Herstory of Breast Cancer: A Mother’s Story” is directly transcribed from one of the interviews. It’s what I call *quoted poetry*. In the editing and graphic design, I’ve attempted to engage in a study of form in/as function. Fundamentally, however, it is *her* experience and *her* story in *her* words.

After my mom shared her “mammogram monologue,” she made an off-hand comment that she’d completely forgotten about that day until we spoke. Only now, as a result of our conversations, had the memory surfaced. “I must have forgotten... that, or I’d chosen to block the memory,” she said. I wonder, how many other memories, how many other stories my mom has blocked or simply chosen not to remember? I wonder if, in my zeal to hear her stories (and “complete” my research), had I opened old wounds (or perhaps new possibilities)?

In *Conversations on the Edge*, Richard Zaner eloquently states, “If grief, in the telling of it and listening to it, is relearning how to be in the world, it is also the beginning of rebuilding the world that’s been shattered by loss.” During one of our interviews, I remember my mom saying that the day she found out she had cancer, her whole life changed. I wasn’t there for her that day. I couldn’t have been. My mom pointed this out to me. But I can be there for her now. In the telling and the listening. In the present.

Interviewing my mother provided a rare opportunity to blend work and family, to share what I love (my research) with someone I love (my mom). Our “interviews” were

conversations as much about her cancer as about our relationship—mother and son at a particular point and time in our lives. One's lazily learning to live in retirement, while the other is busy trudging the road to happy destiny in a Ph.D. program.

To study something is to bring the subject of inquiry closer, to make it part of our lived experience. This assignment provided an opportunity to bring my mom and me closer—bound by illness and constituted in communication. To research is to expand our lived experience. Now, I know more about my mom, and she knows more about her son.

## References

- Broyard, A. (1992). *Intoxicated by my illness*. New York: Ballantine Books.
- Coles, R. (1989). *The call of stories: Teaching and the moral imagination*. Boston: Houghton Mifflin.
- Ellis, C. (1993). "THERE ARE SURVIVORS": Telling a story of sudden death. *The Sociological Quarterly*, 34(4), 711-730.
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press.
- Sacks, O. (1984). *A leg to stand on*. New York: Touchstone.
- Zaner, R. M. (2004). *Conversations on the edge: Narratives of ethics and illness*. Washington, D.C.: Georgetown University Press.