

Inhabiting the Patient Experience: illness and the power of narrative



“The day before Mother’s Day 1989, ... a surgeon I did not know phoned me. ‘You have breast cancer and you better decide quickly whether you’re going to do something about it here...or in Portland.’ With that threat, he hung up.

I instinctively knew in those first few moments of shock and tears that my life had just changed.”

Martha Hall in the artist’s statement for “Holding In, Holding On”

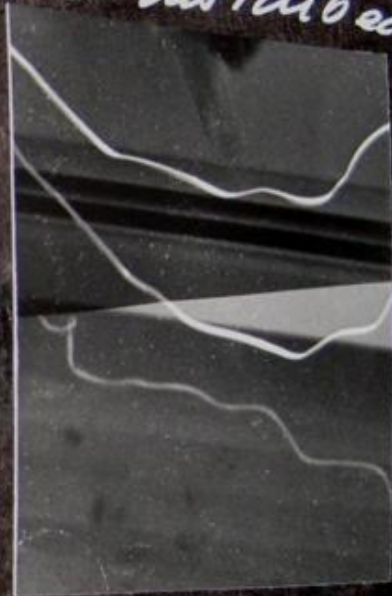
O miss the sun.



O have
dark room
days



disturbed



dreams.

“I was in the process of losing the body I had always known.”

Elizabeth Ettore, from “Autoethnography: Making Sense of Personal Illness Journeys”

“When a person’s life is interrupted by an illness, narrative offers ‘an opportunity to knit together the split ends of time, to construct a new context,’ and to fit the disruption caused by illness ‘into a temporal framework’.”

Susan Bell, from “Visual Methods for Collecting and Analysing Data.”

“Empathy is an understanding of how a disease and its treatment are likely to affect how patients actually live.... Understanding what a disease means to a patient can certainly result in an emotional response, but empathy ... is an understanding based on reasonably complete knowledge of *who* the patient is....

Empathic understanding is a basic characteristic of the true clinician and a fundamental requirement for the full development of practical clinical knowledge.”

Jeanne Levasseur and David R. Vance, from “Doctors, Nurses, and Empathy”

“We took Danielle to Logan on Saturday, then had Gabrielle here Sunday, and of course chemo today. I have shingles and brown tail moth rash so feel edgy and itchy. All my misery is exacerbated by the heat, my low white cell count (1.2) and chemo. (Although maybe the last two are one in the same.)

The medicine for the shingles makes me feel sick – flu-y and longing for sleep.”

Martha Hall to Allison Cooke Brown, June 18, 2001.

The pain in my back is fierce.



“The pressure is on, from doctors and loved ones, to do something right away—kill it, get it out now. The endless exams, the bone scan to check for the metastases, the high-tech heart test to see if I’m strong enough to withstand chemotherapy—all these blur the line between selfhood and thing-hood anyway....

As my cancer career unfolds, I will, the helpful pamphlets explain, become a composite of the living and the dead—an implant to replace the breast, a wig to replace the hair. And then what will I mean when I use the word ‘I’?”

Barbara Ehrenreich, from “Welcome to Cancerland”

L·O·N·E·L·Y

O·N·E·R·W·H·E·L·M·E·D

T·I·R·E·D T·I·R·E·D

“...most people still go to physicians looking for help for existential pains, for the suffering of living in this world, for ailments that no technology can correct. That is where the patient’s story comes in, for it can reveal what is important in the images the doctor obtains. ... Listening goes straight to the heart and helps to create empathy. Empathy opens our eyes to let us see what the CT scan has missed.”

Howard M. Spiro, from *Empathy and the Practice of Medicine*

“The medical establishment tells me I have ‘failed’ a number of therapies. That’s not right: The establishment and its therapies have failed me. The system we live in as metastatic breast cancer patients is simply not designed to deal with the cycle we are living and dying in. The estimated 40,000 women (and a few men) who die annually can’t wait years for FDA-approved, ‘gold standard’ clinical trials. We’re dying now.”

Laurie Becklund, from “As I Lay Dying”

Imagine that you have been told that you have metastatic cancer and you have a short time to live.

What comes up for you?

How do you feel?

Write down some words that emerge as you sit with that scenario.

CASE:

Martha Ann Hall

born: June 4, 1949 (Malden, MA)

April 1989: discovered a lump in her left breast

May 1989: diagnosed with Stage I breast cancer

May 1989: lumpectomy

June 1989: mastectomy; 40th birthday

July – December 1989: chemotherapy

July 1993: pain in shoulder; tests; Tylox; physical therapy; steroids

July 1993: recurrence: metastatic breast cancer, Stage III

July – September 1993: hospitalized at Maine Medical Center for three rounds of high dose chemotherapy

October 1993: bone marrow transplant postponed

November 1993: bone marrow transplant at Dartmouth Hitchcock Hospital

January 1994 – March 1994: six rounds of radiation to hip, neck

July 1998: lump in neck; biopsy

July 1998: recurrence: Stage IV metastatic breast cancer

July 1998: radiation (twice a day for two weeks; skip a week; repeat 4 times)

Spring 1999: pain in ribs

Summer 1999: intense pain in ribs

September 1999: cancer in hips, spine, skull, ribs, liver

September 1999: begin weekly chemotherapy

2000: retired due to illness

recurring

Will I live to be 60?

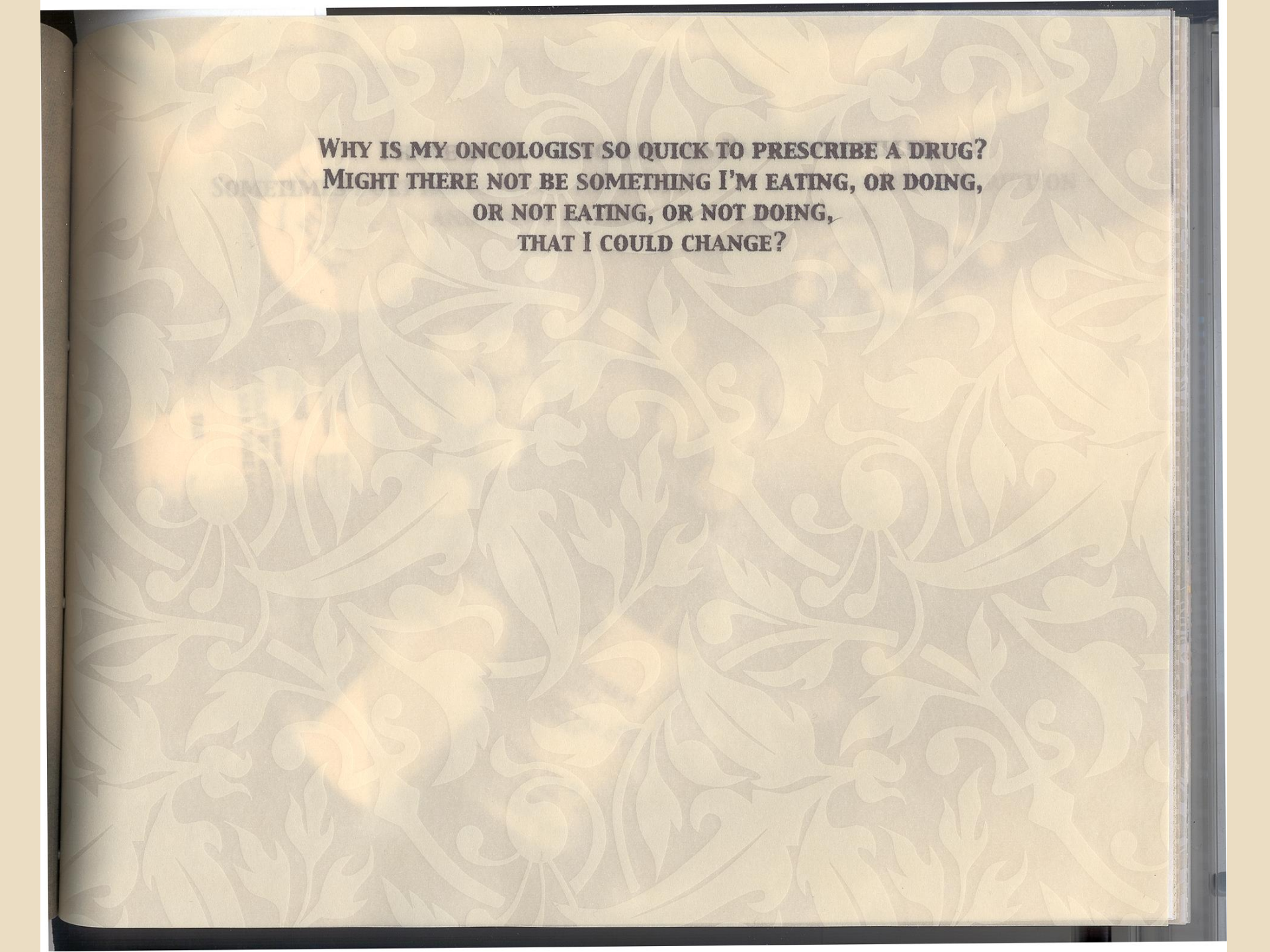
recurrence

Take a look at the pages from Martha's books on your tables. Imagine that she is there telling you her stories, expressing the emotions in the books.

How do these narratives impact your plan of action?

How do they impact your feelings about Martha?

Do they change your feelings about yourself as a practitioner?



**WHY IS MY ONCOLOGIST SO QUICK TO PRESCRIBE A DRUG?
MIGHT THERE NOT BE SOMETHING I'M EATING, OR DOING,
OR NOT EATING, OR NOT DOING,
THAT I COULD CHANGE?**

“What I don’t want to hear about:

hair loss

palliative treatment

metastases

lung damage

heart damage

radiation-increased risk of recurrence

slash and burn

survival rate

odds

life expectancy

life insurance refused

memory loss

chemo-induced menopause

...”

Martha Hall, from “Black Box”

I imagine skin as textile, as text.
A reading of the history of the body.
A sum of our experiences, imprinted
upon our surfaces.

You and I have had so much happen
to us, beyond others of our age,
and our bodies speak volumes of
these events. Masectomies, bone mar-
row tests, chemotherapy, radiation,
reconstruction. . .

Our skin reveals the map of our per-
ilous journey into middle age.

“Do you see
what
you
fear?”

Martha Hall, from “Jane, with Wings”

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