

Breast Cancer and Its Metaprescriptive Utterances: Some Feminist Perspectives

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Abstract

Opening up space about bodies and disabilities in socio/applied linguistics, this paper offers a critical discussion about some key metaprescriptive utterances (Lyotard 1984) around breast cancer to argue that these terms elide the lived, material, corporeal realities around bodies and the spillage that cancer entails. Based on first-person accounts by women who have had to deal with breast cancer and its treatments as well as those of their partners, the paper explores two issues: 1) ways in which women appropriate medicalized colonizing tropes, specifically chemotherapy, amputation, and prosthesis to speak of them in relation to what these terms mean in the exigencies of their everyday lives, and 2) alternate critical interpretations of these terms that permit us to begin dis-assembling our collective ideas about 'disability,' and 'normalcy.' Drawing on feminist and other philosophical perspectives, the paper also discusses issues relating to medical gazes, (male) fetishism about breasts, and societal notions about 'abject' bodies.

Key words: *language, disabilities, bodies, critical perspectives*

Background

Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (Sontag, 1974, p.4)

I am a post mastectomy woman who believes our feelings need voice in order to be recognized, respected, and of use. I do not wish my anger and pain and fear about cancer to fossilize into yet another silence, nor rob me of whatever strength can lie at the core of this experience, openly acknowledged and examined. (Audre Lorde, 1981, p.6)

In the intimate public space of the Breast Cancer waiting room...women held their heads at odd angles and fixed their gazes on distant points in a largely unsuccessful attempt to avoid seeing—and knowing—too much about those who waited on them. Patients returned from their mammograms and waited either to be released or be rescrutinized and diagnosed; as they waited, still in their hospital johnnies, their private stories became an unwelcome form of public property. An older woman with a persistently fixed smile and shock of white hair was called back by nurses for the third time; as she rose stiffly from her chair, the rest of us found ourselves watching, exercising the 'power' of a look that offered no pleasure. Although the flimsily tied hospital gown marked the site of the white-haired woman's vulnerability to the scrutiny of a public gaze that threatened to expose the contours of her body, the repeated visual marker of that distinctively patterned gown also signaled a collective susceptibility to illness and death not located on an individual body but diffused and projected throughout the waiting room. (Tanner, 2006, p.79)

Linked as they are by concerns about bodies, the above quotes point to three distinct orientations to ill health, with Sontag's excerpt needing to be understood against her larger argument about the traumatic nature of life-threatening ailments which force us humans to confront the "night side of life" (1).

According to her, societal metaphors permeate talk about women's bodies and cancer—with breast cancer often viewed as *insidious, invasive, and unspeakable*—and women find themselves in spaces where they have to both acknowledge and counter these tropes. If cancer can be stripped of negative metaphors and 'de-mythicized,' Sontag points out, ill people will stand a better chance of avoiding stigmatization and addressing cancer on their own terms (Sontag 1974, pp.86-87).

Lorde's excerpt in contrast is a voice speaking back, refusing to clamp down her fear and anxiety about cancer. Speaking from a feminist, African-American, and lesbian perspective, she challenges the patriarchal discomfort about speaking about women's bodies, and writes openly in *The Cancer Journals* about her refusal to wear a "grotesquely pale prosthesis" and conform to societal expectations of what a 'normal' woman's body should look like. Although she acknowledges the pain and fear accompanying the illness, she chooses to mine "whatever strength can lie at the core of this experience," and writes reflectively of what it means for her as a lesbian woman of colour.

Tanner's piece, in contrast to the other two, speaks of waiting spaces that women with cancer find themselves. Openly articulating the deep discomfort that a lot of us women have encountered in waiting rooms awaiting our turns for mammograms, dressed in flimsy hospital garb that permits little privacy, aware that our body parts are up to public gaze now, she writes of the medical waiting room that "uncovers the body's vulnerability to illness and injury along a continuum that ranges from the physical...to the symbolic..." (2006, p.65). The apparently empty space of the waiting room—where uncertainty and anxiety prevail most palpably—is, as Tanner points out, the cultural stage where our assumptions about bodies, ailments and dying are held up to the light and rendered visible and audible.

All three orientations allow us to speak to specific language-related issues around women's bodies and cancer from different angles, with some permitting laminations of issues that others do not. Taking as its point of entry the (oral and written) published autobiographical accounts of women with breast cancer, as well as accounts of their partners, this paper seeks to bring *metaprescriptive utterances* (Lyotard 1984); addressed in detail presently) about cancer and women's health/bodies into focus. This focus builds on previous work in applied linguistics on bodies, food, narratives and language (Bamberg and Andrews 2004; Cook 2004; Cook et al. 2004, Gee 1990), as well as scholarship relating to ailments and medical domains (Sarangi and Roberts 1998, Hall, Slembrouck, and Sarangi 2006, Higgins and Norton 2009), aging (de Bot and Makoni 2005), Makoni and Meinhoff 2003), Alzheimer's disease (Davis 2005; Hamilton 1994), Author 1995, 1997, 2008a, b), and diabetes and epilepsy (Author and Makoni 2008). Theorizing about bodies in general, though, and our languaging of experiences regarding them is quite recent (Hall and Bucholtz 1995; Livia and Hall 1997, Mills 2004), and the present discussion builds on this area as well.

My aim with creating some textual space for such accounts is not so much to theorize narratives or narrative 'truths' (see De Fina et al. 2006; Johnstone 1996, 2000, 2006; Menard-Warwick 2002, 2004, Pavlenko 2003, 2007, Kramsch 2000, 2003, Kramsch and Lam, 1999, Hall and Bucholtz 1995, Gee 1990 for excellent discussions); neither is it to address what of the illness comes through in the narratives (we know much of that from cultural, bio-medical discourses). Instead, it is to shift attention to how it is *through* the body and particular languaging of it that we learn about: a) how breast cancer patients appropriate medically-dominant *metaprescriptive utterances* (Lyotard 1984; more on this presently) about their bodies to move beyond it (Manderson and Stirling 2007), and 2) how probing the normative interpretations of these utterances brings in to view alternate laminations—including the uncontainability and spillage of illnesses--that otherwise tend to remain invisible. Two key questions that the paper will address then are:

1. Where do our prescribed notions of cancer and women's bodies come from and in what ways do they become gazes that bind?
2. In what ways does a probing of breast cancer metaprescriptive utterances permit alternative interpretations of bodies and illnesses? How do breast cancer patients appropriate some of these medical metaprescriptive utterances to speak back, and what are some of the issues that float into view as they do so?

I will attempt to address the first question by offering a partial conceptual canvas that makes connections between medical discourses, societal tropes, the role of science in the normative conceptualizations of bodies, and the binding effects of these 'gazes.' The second set of questions will be explored in and through interpretations of breast cancer patients and their partners of their bodies and ailments.

These questions mark a shift in perspective about illnesses and narratives, a move that is not trivial in socio/applied linguistics. There is a shroud of silence in the discipline about several of the issues here—bodies, terminal illnesses, mortality—and this paper probes the edges of this blanket to move them from the incidental space they currently occupy to those as central as gender, ethnicity and class. Disabilities, illnesses, ailments and our ability to live our everyday lives depends crucially on our bodies ‘working’ ‘for’ us; our everyday negotiations in our jobs, relationships, in the world hinge on our ability to wake up each day and trust that our bodies will not betray us. Bodies and societal and bio-medical orientations to them are hopelessly intertwined and a powerful way forward towards addressing their knotted nature, is, as Johnstone (1996) puts it, to frame questions about the social world in terms of the individual. Issues about breasts, cancer, medical/male gazes, and our collective societal notions about ‘normal’ ‘attractive’ bodies need then to be addressed in terms of individual voices (De Fina, Schiffrin and Bamberg, 2006).

Prescribed notions of illnesses, bodies, ‘able-ism’, metaprescriptive utterances, gazes

Drawing on the feminist insights of writing by people whose excerpts head this paper as well others (Mills 2004),¹ the present discussion will speak to three metaprescriptive utterances around breast cancer—*chemotherapy, amputation, and prosthesis*—that emerge in the accounts of some of these women. Metaprescriptive utterances, as Lyotard thinks of them, are prescriptive statements that describe what the rules of language use or languaging must be in a given domain (medicine in the present case). Lyotard offers *paralogy*—a focus on the local, the anti-method—to counter the rationality, deterministic orientation, and denotative statements of science. He says:

The function of differential, or imaginative or paralogical activity of the current pragmatics of science is to point out these metaprescriptives (science’s ‘presuppositions’) and to petition the players to accept different ones. The only legitimation that can make this kind of request admissible is that it will generate ideas, in other words new statements (Lyotard, 1984, p.65).

The present exploration probes particular metaprescriptive utterances drawn on prescribed medical and societal discourses about breasts, cancer, and bodies in general

to engage in the paralogical, an alternate set of interpretations that do not otherwise find adequate articulation. Not by any means discrete, the various discourses around these metaprescriptive utterances are knotted around anxieties about invasive surgeries where the speaker has to negotiate her body and self in medicalized spaces and language, about bodies betraying its containability with blood and fluids leaking, and where mastectomies and reconstructive surgeries speak to issues beyond amputated body parts and prostheses.

In terms of their societal roles, these prescribed medical and societal discourses are all about ‘gazes’—ways of seeing/interpreting/judging—that medical and societal discourses have perpetrated, that have colonized the ailing conditions, and which these women appropriate (have little choice but to) in order to speak back. When emanating from medical domains and the larger culture, these metaprescriptive utterances have the potential of trapping people in emotional spaces. Michel Foucault’s *The birth of the clinic* raises questions about how the gaze is constructed in medical domains, how particular ways of viewing, thinking about, languaging the body shape what and how doctors—indeed, entire medical personnel (nurses, pharmacists) see. He defines the split between the patient and medical work that is so much a part of the modernist world as follows:

Paradoxically, in relation to that which he is suffering from, the patient is only an external fact; the medical reading must take him into account only to place him in parenthesis. Of course, the doctor must know “the internal structure of our bodies”; but only in order to subtract it, and to free to the doctor’s gaze “the nature and combination of symptoms, crises, and other circumstances that accompany diseases.” It is not the pathological that functions, in relation to life, as a counter nature, but the patient in relation to the disease itself...Hence the strange character of the medical gaze...It is directed upon that which is visible in the disease—but on the basis of the patient, who hides this visible element even as he shows it (1973, pp.8-9).

In order for the disease/malfunctioning body part to be treated, the medical gaze ‘whites-out’ the human voice to focus only on the diseased body. This plucking out and reading of the body part—rendering it visible, while simultaneously casting human subjectivity in the shadows in the medical

domain—is what often leads the patient to feel abandoned to the dehumanizing metaphors, and vulnerable, to be talked about solely in terms of her diseased body parts instead of how the body part is intimately a part of her very existence. Based on Foucauldian reasoning, Herzlich and Peirret (1987) also write of how science replaced religion as a key discourse through which health and illness got represented. Starting from the 19th century there emerged a rhetoric oriented to seeing the body as a mechanistic object, whose body parts could be repaired when they broke down. Scientific knowledge—medicine in this present case—got languaged in very specific ways. Presented largely in terms of denotative facts (Lyotard 1984), science distinguished itself from other forms of knowledge by claiming to be “objective,” by offering a set of denotative statements with a literal orientation to language, open to others for observation, to be judged by experts so as to be found “valid” and “reliable.” As Stacey (1997) explains, “what makes knowledge scientific is its reference to something external to itself described in a language which can be scrutinized by others with similar training and qualifications” (p.231).

It is these denotative statements—seemingly objective realities, ‘facts,’—that, according to Lyotard, make up the power of, and are behind metaprescriptive utterances (see Hall, Sarangi and Slembrouck 2005 for an excellent account of institutions wielding power over patients, especially children).ⁱⁱ The power of the medical experts and the authority vested in medical personnel mandate the ‘visible,’ ‘what can be seen’ and thus talked about. This visibility factor—what we see—and the harsh dynamics of what we see, where we would sooner construct unidimensional, simple pictures instead of addressing ailments as multiple, heterogeneous domains is part of our destructive gaze because we have bought into metaprescriptive utterances handed down to us by the medical world. When the body wears discernible evidence of an ailment—a head shaved because of cancer, the gaunt look of Hepatitis C or AIDS patients, the diffident shuffles of those with hip surgery, this gaze (including the one present in this writing) finds ‘residence’ (so to speak) in a body that seems to partially signal its identity in terms of debilitating condition. The medical gaze, of course, exaggerates this tendency in its various contexts to where the person with the ailment (and in some cases their partners as well, as the present paper will show) is pushed into assuming ‘the speak’ of medical practitioners, participating thereby in absenting themselves in their presence, speaking of their body parts in the language that is coming at them, thus denying the spillages around their bodies.

In more recent years, however, the medical scenario has become more complicated. While early historical tropes around the body viewed it as a delicate system that a medical expert could intervene in and treat, more recent tropes insist that the delicate balance of bodies is one that individuals (and their partners) need to monitor by making themselves literate about a lot of wide-ranging information. As Stacey (1997) points out, “The individuals charged with this onerous responsibility must learn to read their bodily texts through modes of self-knowledge and exploration. The patient is required to develop a sophisticated therapeutic literacy to develop his or her well-being accurately” (229).ⁱⁱⁱ Also, illnesses have assumed individualized overtones. “Kept in a state of heightened awareness about the rapidly proliferating number of local and global risks and dangers to the healthy body, we are easily seduced by fantasies of individual agency, autonomy, and self-generation (Stacey, 1997L 22&). Individual responsibility about one’s body becomes a pressure of sorts, and cancer, especially, has rings of such individualized discourses about it. Herzlich and Peirret maintain that:

Cancer is the prototype illness of our time—*cancer is the illness of individuals in their relations with society*. It is indeed the illness of the individual but this individual can only be conceived of in relation with society as a whole. At the same time cancer is also an illness produced by society, but one that manifests the flaws of the present-day individual (1987, p.62)

This emergence of the “patient-as-responsible” rhetoric has simultaneously shifted the role of the medical expert in some ways. The proliferation of medical information now available to the lay person—presented as it is in easily accessible language and small bites of information—in some sense works to diminish the role of the expert, with patients deciding for themselves whether or not they need “second opinions” on diagnoses, and with doctors themselves consulting other doctors about prognoses. Ownership of such specialized knowledge has become more distributed than before, a diffusion that Lyotard (1984) maintains has threatened science’s legitimacy,^{iv} because the power associated with the medical world’s language is weakening as patients know more and more of it (as is evident in the narratives of patients with breast cancer who draw on the metaprescriptive utterances about their cancer and their body parts to speak back).

Details about the present endeavour

The material on which the present discussion is based is drawn from an extensive pool of ailment/disability-related data. Gathered over the last 4 years, these materials range from oral and written narratives by patients and their partners with a variety of ailments (including type-1 diabetes, epilepsy and Alzheimer’s disease) as well as close analysis of bodies and impairments by the newsmedia (Ramanathan 1997, 2008a, 2008b, 2009), to field observation and participation in key medical sites (pharmacies, doctor’s offices, health insurance policy offices, hospitals). My investment in this general area is deeply personal as well: I am the long-term partner of one with a serious chronic ailment, and have had to wrestle with illness-related issues from the stand point of a caregiver.

It is against this data canvas that the present sub-set of data—the first-hand accounts of breast cancer patients and their partners—needs to be understood. My choice of written narratives is deliberate as indeed is my choice of narratives I have chosen for the present discussion. My opting to focus on written form stems partially from wanting the kind of reflection and retrospection that (on-the-spot) oral narratives may not engender (see Ramanathan 2009 for a discussion of this). Furthermore, to complicate the canvas, I wanted to bring in partners’ views on bodies (particular breasts), and these were more easily available in published form. While my sub-pool of texts on breast cancer comprised a total of 12 published books and a host of media-related articles on it, I have picked out the following five to center the present discussion around, since they seemed to best represent a range of issues around gender, ethnicity, and sexuality while also speaking to the corporeal realities of breast cancer:

1. Audre Lorde’s *The Cancer Journals*, 1997, San Francisco: aunt lute books
2. Marcy Jane Knopf-Newman’s *Beyond slash and burn and poison: transforming breast cancer stories into action*. New Brunswick: Rutgers University press, 2004 (Knopf-Newman 2004)
3. Mark Weiss’s *When your wife has breast cancer*, Berkeley: iBooks Inc. 2006 (Weiss 2006)
4. Barbara Stevens *Not just one in eight*. Deerfield Beach, FL: Health communications Inc., 2000 (Stevens 2000)
5. Segments of Jackie Stacey’s *Teratologies*, NY: Routledge, 1997.

As mentioned earlier, my discussion centers around: 1) chemotherapy, 2) amputation, and 3) prosthetic body parts—metaprescriptive utterances that simultaneously present distinct views about women’s body parts and cancer while also concealing uncontainabilities and spillages.

Chemotherapy

I begin this section with what Susan’s chemotherapy sessions meant for her and her partner in terms of the changes they brought on in their lives and relationship before addressing issues relation to the metaprescriptive term itself. Here is how both of them describe chemotherapy:

Susan’s narrative	Robert (Susan’s husband)
<p><u>Chemotherapy is awful. I felt sick, like having the flu; moreover, I felt as though I was being slowly, methodically poisoned. I would lay in the dark in my bedroom, with a towel over my head feeling very nauseated. Compazine, an anti-nausea medication was ineffective, because I still vomited. In fact, all it did was make me tired. The only thing that helped me was smoking a little marijuana given to me by friends. When I looked at myself in the mirror I saw a woman with dark circles under her eyes...</u></p> <p>My attention span those first few days was very erratic. By the fourth day I was beginning to feel good again. In the meantime, my house</p>	<p>Although our communication wasn’t great, I thought friendship had been pretty strong until the time Susan got sick. I had gone to all her doctor’s appointments including the consultation with her oncologist. <u>I assumed we would go together for her first chemotherapy treatment. I assumed we would go together for her first chemotherapy treatment. When she told me “My mother’s going with me” I not only felt as though I had been kicked, but I felt left out. A couple of other times I asked if she wanted me with to come with her and I guess she must have said no. So other than going with her to one radiation treatment, I never asked or went again. It was not until later that I found out it</u></p>

would be in utter chaos. Robert could not deal with my illness; consequently, he was never home. As a result my two boys, Charlie, age ten at the time, and Matt age six would be running throughout the house, all the televisions would be on and junk food would be everywhere.

...

Robert and I have been together twenty-two years, twenty of them married. The last five have been a challenge; this last year very rough. My getting breast cancer put more of a strain on the relationship....It is too scary for him to comprehend so he buries it, and escapes by going to the office. His behaviour was one big surprise through this whole thing....Finally, I said to him, "if you can't help me personally or emotionally, could you at least handle the bills and the paperwork for the insurance? Will you make sure claims are filed and that the doctors get paid?" It turned out he didn't even do that or if he did he was not very thorough. This last year has been a nightmare and the clinics and doctors are threatening to sue me.

We have made the decision to separate. I feel good about this decision because now I can move forward as I need to for myself and for my children. I am in a state of self-awareness where I am striving to be happy and want to be fulfilled. I don't want to live my life full of anger, resentment and hostility, which is how I feel after the way he treated me. Robert is still running. Truthfully, I don't think he wants to believe that my wanting a separation has anything to do with him. He believes I am just going through a crisis. (33-34)

From: Susan Alexander's "I thought I had a good marriage" in Barbara Stevens *Not just one in eight* (2000)

had affected her that I hadn't gone with her to anything but by then it was too late.

...

Having the financial burden solely on my shoulders was frightening. Nobody ever talks about that or all the other things that have to be taken care of: picking up the kids after school, making meals, having someone come over in the evening for a few hours so that the partner can go out for a bit to do whatever. ...That is why I think it is a good idea to sit down with family or friends, or whoever is part of your support system without your partner, and tell them that you need their assistance to help ease the pressure somewhat. Sometimes a spouse is uncomfortable asking for help because they are not *his* family...

It's frustrating having 'to be the man', having to be strong. Women have certain expectations about men and the way they think men should behave...Perhaps we need to take a deep breath and tell the woman "I am just as fragile as you are. I know that is not how I come across. You might think I don't care, but may it is because I care so much, and am so afraid that I run." Sometimes it is perceptions that are wrong, what they think is going on, isn't. I am partly to blame as I should have talked about how I was feeling. ...Communication helps prevent misunderstandings which too often can create more of a problem. I would say "tell your partner how you are feeling, because it is not just them who is going through it, you both are. Don't try to be a superman." (35-38)

From: Susan Alexander's "I thought I had a good marriage" in Barbara Stevens *Not just one in eight* (2000).

Several issues emerge in both narratives around "chemotherapy": Susan's frustration at her husband not being able to deal with the house and kids, her disappointment at his not taking care of insurance and policy claims, and her decision to separate because of the 'resentment and hostility' she feels against him. In Robert's case, issues around chemotherapy assume nuances around who was going to accompany Susan to the session (himself or her mother), picking up the responsibilities around the house and kids and feeling frustrated at being locked into a 'male' role and his general inability to communicate his conflict. These are issues that the metaprescriptive term of 'chemotherapy' draws a veil over and the radiating ripples around this term/event stay hidden.

But beyond this unhappy, difficult spillage are the linguistic and etymological aspects of the term itself. The word 'chemotherapy' is a combination of "chemo" and "therapy" with the former being derived from "*chemo*" meaning "chemicals but specifically in this instance chemicals which have 'a toxic effect' and the latter from *therape* meaning "treatment" or "cure." The juxtaposition of seeming opposites—a toxic compound that kills (chemo) with a treatment that cures (therapy) is reminiscent of Derrida's *pharmakon* wherein the remedy and the poison are part of each other; the term means both poison and cure. While Derrida views writing as a *pharmakon*, both a remedy to relieve overburdened memo-

ry and while also a dangerous drug (in the Socratic sense), the idea that the opposite is already built into the term is relevant here. We need to ask

what it is that leads for the use of a single word for opposing meanings, and though we are here in the realm of speculation, it is not unreasonable to infer that it may be because one of the terms contains the other; the cure 'contains' the disease inasmuch as it 'contains' or restricts it and contains it inasmuch as it actually worsens [or even causes] the disease. The prolonged use of interferon injections for Hepatitis C, for example, can lead to malignancy in the liver in five per cent of cases. That is, the cure contains disease; it's not difficult to see why 'pharmakon' is both.

In the case of 'chemotherapy'—a real drug administered to cancer patients—this opposition, or, as it turns out, non-opposition, is lived out: the 'therapy' patients actually receive makes them ill (as Susan points out in her narrative), and when administered to non-cancer patients (as in the case of curing Hepatitis C), chemotherapy actually causes cancer. I stress these issues around etymology and morphology here to highlight the rift or gap between these terms that otherwise go unnoticed. *Chemotherapy* has become a metaprescriptive utterance with particular associations and specific conceptual apparatus that begs to be texted and infused with new associations and meanings (see Wikipedia on this term, for instance). As Culler points out (1982), this practice of relying on the terms of an opposition in one's argument (chemo+therapy in the present case) while simultaneously seeking to displace that opposition permits the possibility of new meanings, a point that Derrida discusses in his sections on "paleonymics": the retention of old names while grafting new meaning upon them.^v Opening up 'Chemotherapy' and its various normative predicates to interpret it in the more grounded space of a narrative of a patient and her partner permits one to both resist the prior dominantly biomedical and societal associations around it while also opening doors for life's related messiness to float into our view (as in Susan and Robert's narratives). It forces us to acknowledge, as Deshazer (2005) points out that "the treatments may be invasive, indeed poisonous; their medicalized bodies may strike them as frail and unfamiliar; the stigmatization they face and the pain they experience may be debilitating; the promise of victory may ring false" (p. 15). To move from a linguistic taking apart of the elements of a word understood denotatively to the repercussions of the connotations it has acquired is to see more than just the body of the patient who suffers. The intensity and anxiety associated with the word itself, knowledge that the cure entails the death of one's tissue and the loss of one's hair and energy are connotations functioning in such a way as to threaten the social fabric of the family. It prods us into probing gender-related dynamics—Susan in the above instance is left dealing with concerns about the house and kids and speaks of Robert losing himself in his work; Robert, as mentioned earlier, finds himself trapped in a 'male' role feeling pressure to behave in particular ways. The chemo (the toxic chemical) that is intended to cure the body, poisons familial relations, becoming thus the 'therapy' that isn't.

We need to ask whether these metaprescriptive terms require to be changed, or if they cannot (seeing how completely dominant they are of bodies and ailments) what we can do to make room for paralogical—more localized, alternate—accounts that illuminate both the extent of these colonizing tropes while also making room for them being countered and spoken back to. Doing so leads to the cultivation of a discourse that is at once more holistic and expressive, wholly antithetical to the kind of discourse demanded of scientists at the time of the founding of the Royal Society in Britain (Atkinson 1998). Scientists were then exhorted to use plain simple language and dispense with flourishes of rhetoric which feed the imagination rather than the cold observing intellect—the birth of the purely denotative. It was imperative to separate myth from empirical fact if science was to take the course it did; but there was an accompanying impoverishment, the loss of a richer more uncertain 'surround'.

Amputated bodies

If metaprescriptive associations around *chemotherapy* are partially about the conjoining of opposites, amputation relies on another set of polarities, namely those relating to "losing a part to save the whole." Much of the language regarding amputation that we collectively have in place emerges from concerns regarding sites of amputation, infections that prompt it (gangrene, severe injury, a tumour), and rehabilitation after surgery (a theme often associated with soldiers losing body parts). In the case of breast cancer, where one or sometimes both breasts get amputated, the local articulations assume nuances relating to sexuality, sexiness, and one's public image (Livia and Hall 1997). Breast cancer patients and their partners seem to find themselves speaking simultaneously, to be claiming particular subjectivities in the face of cancer's uncertain and onward march; while also resisting societal meta-

phors around “attractive’ sexual bodies, they seem to have little choice about the ‘lose-a-part-to-save-the-whole’ discourse of medicine, points that emerge in Barbara and Bart’s (Barbara’s partner) narratives below:

<p>From: Barbara Stevens: Breast cancer really is a wake-up call!</p> <p>Barbara: I have since thought, How odd I never said goodbye to my breasts. It was a day of experiences and wonderful people. Two examples are: as I was being wheeled into the operating room one of the staff held my hand. I cannot express how comforting that was. I made terrible jokes to my medical team. Things such as never having breast pain again. The anesthesiologist who came to visit the next day told me I had nearly given him a heart attack when I started in on Dr. Kevorkian jokes.</p> <p>I was freezing when I woke up. My chest hurt terribly. Not from surgery, but from the bandage that was wrapped so tightly around me. My nurse was wonderful. She rubbed my back because it hurt. I was unable to lie on my stomach because of the surgery or my sides because of the drains. When Bart came to visit early the next morning he crawled into bed with me and we went to sleep in one another’s arms. Neither of us had slept the night before. My husband is the most wonderful, caring, gentle man I have ever known. (p. 6-7)</p> <p>From: Not just one in eight: stories of breast cancer survivors and their families</p>	<p>Bart, her husband:</p> <p>Barb does not remember her surgeon showing us pictures of women who had undergone mastectomies so that we could be prepared. That is one of the reasons I went with her to all her doctor’s appointments. There were things both of us missed. I agreed with her decision to remove her breasts. Had she not done she would have lived her whole life wondering, “When will I get it in the other breast”? I have no doubt she would have.</p> <p><u>When her bandages were removed the day she was discharged from the hospital I knew the best way for me to handle it was t look directly at her scars and get used to them. You know what? I looked and thought “ No big deal! She looked great. She just did not have breasts, and I thought, Barb still looks sexy! After a while I no longer saw the scars.</u> (p. 8-9)</p> <p>From: Not just one in eight: stories of breast cancer survivors and their families (2000)</p>
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Barbara’s line about not saying “goodbye to her breasts” coupled with Bart’s articulations about “getting used” to her scars and regarding their removal as no “big deal” speaks of their need to recognize each and the other’s body, a point that has significance for the complex intersection of bodily contingencies and identity construction. Lorde voices similar dilemmas in *The Cancer Journals* where she insists that “any amputation is a physical and psychic reality that must be integrated into a new sense of self,” (16) and writes: “I would lie if I did not also speak of loss...the absence of my breast is a recurring sadness, but certainly not one that dominates my life.” Stacey in *Teratologies* speaks of the narrative of her body after her cancer surgery and says:

The narrative of my body continued to be rewritten at each stage. As I lay recovering from surgery, I tried to find out what had been removed apart from the tumor. The surgeon had taken out the tumour and also the fallopian tube and the ovary on the right side. Overnight my identity was reinvented: I was now a cancer patient; or was I? I was told the disease may or may not still be present in my body. It may or may not return. (p.4)

Stacey’s questioning about who she now was in relation to her ailment and body after surgery captures something that is hinted at in Barbara’s narrative: the tumult of having one’s sense of self overturned by a dominant medical metaprescriptive utterance (of both being a cancer patient and having a body part removed) while also speaking agentively of trying to reconceptualize herself. Like Stacey and Lorde, Barbara’s lines, where she speaks of her joking with doctors about not having any more breast pain, also captures degrees of agency, with the forward-looking, positive orientation she is giving to what is otherwise a traumatic “wake-up” call. While Stacey goes on to muse, “The past must now be reimagined and rescripted. ...Given the demands of new bodily evidence, I found myself inventing stories about myself...The body tells a new story and so demands a reinterpretation of recent

life history (p.5),” Barbara speaks of the present moments where her loving husband crawls into bed with her after her surgery, and where the removal of body parts (both breasts) has saved her life.

This point about re-cog-nizing one’s changed body and recent past—including the removal of breasts to save life--is echoed in feminist narratives that challenge the “normal body gaze” of absent breasts. Garland Thomson’s discussion (2002), for instance, speaks to how contemporary feminist narratives resist “the sexist assumption that the amputated breast must always pass for the normative sexualized one either through concealment or through prosthesis. This either-or orientation about a feminine body-part gets countered by the “It’s no secret” poster used in an advertising campaign by the Breast Cancer Fund that portrays a single breasted female flaunting her mastectomy scar in a provocative pose similar to models advertising Victoria’s Secret lingerie. (Surely, the ‘secret’ in the poster is intended to play on the ‘secret’ of Victoria’s Secret?).

As DeShazer (2005) points out about this poster, “the amputated breast is not only revealed, it is ironically sexualized in a manner that implicitly critiques soft-porn representations of women’s fetishized breasts, artfully bared” (p. 28).

This point of “fetishized” breasts, of course, raises concerns about bodies with amputated breasts being “unattractive and asexual,” (Bart above needing to convince himself that Barbara still looked sexy, for instance). Inextricably tied to male gazes (Hall and Bucholtz 1995) that view breasts as ‘attractive’ objects, issues around restoring a female body to its ‘original’ form can be seen to be tied to associations around personalized body horrors and ‘ugliness” (Kristeva 1982). The following narrative of a husband whose wife underwent a mastectomy articulates his concerns about his wife not having two breasts and about his coming to terms with her not-so-beautiful-anymore body:

From: *When your wife has breast cancer: a story of love, courage, and survival*
By Mark S. Weiss 2006, NY: iBooks
Speaking about his experience in a support group:

The guys for the most part talked candidly and emotionally about their experiences with chemo or with surgery. One guy spoke about his wife’s cancer being misdiagnosed at another hospital and his feelings of frustration and guilt for not questioning the doctor who initially screwed it up. To my discredit, I didn’t read the room correctly; this group was focused on the survival of their spouses, the acute issues and I should have respected this. No one in the group really spoke about the private things that I felt only husbands in our situation could really feel. Sexuality had to be one of those items, yet the discussions didn’t go there.

When it was my turn, I took a chance and spoke about my desire to know what type of breasts my wife would end up having after the reconstruction process, thinking that this would start a discussion about the sexual consequences of cancer treatments. The guy to my right began radiating hostility at me for initiating this type of discussion. He was about sixty years old and probably thinking that I was a shallow, uncaring little SOB whose paramount and only concern should have been my wife’s survival.

The guy actually interrupted me twice, stating that his love for his wife far outweighed something as petty as the appearance of her breasts. He seemed to hold sway with the room because I felt it was eleven (including Roz) against one. I suddenly felt identified with Henry Fonda in *Twelve Angry Men!* His hostility also sparked my sense of defiance as I defended myself by telling the group that I loved my wife completely, and was focused on both her recovery and survival and on protecting my kids. I also pointed out that every time I went to the reconstructive plastic surgeon’s office and looked at his book of pictures of reconstructed breasts, I saw pictures of overweight, post menopausal women with youthful looking breasts that didn’t quite fit. I wanted to see pictures of young, beautiful women with reconstructed breasts because my wife is young and beautiful. I explained that if the new breasts weren’t going to be beautiful, then I wanted to start coming to grips with that now and not be disappointed later...

After that meeting, Richard and I walked uptown together and had a pretty open conversation about sex and intimacy, and it actually validated my feelings of concern. It also validated my feelings that it was OK to hope to have an even more beautiful and happy wife at the end of the treatments and surgery. During the fifteen block walk, Richard took me from feeling like an uncaring piece of garbage to feeling like a normal man with normal concerns. I felt very lucky to have the opportunity to speak so candidly with someone, and I was very happy that he was able to lift my spirit after such an uncomfortable experience. (p. 102-104)

Mark Weiss's open and honest articulation of his desire to have his wife's body 'restored' with reconstructive surgery (addressed in more detail in relation to prosthesis in the next section), evokes a mix of reactions. On the one hand we can intuit his (male) insistence that a woman's body have two breasts and be a certain way (something that I, as a woman, recoil from). On the other hand, though, his anxieties are bringing to the surface some key implicit assumptions about bodies, "normalcy," and "deviance" that we have collectively assembled. His utterances about "overweight, postmenopausal women with reconstructed breasts" are an articulation of the 'horrors' that perhaps mark the significance of the various boundaries and orifices of the body, a key premise for discourses of abjection. Kristeva critiques the cultural, political and historical conditions under which 'clean, obedient, law-abiding, decent bodies emerges. Abjection for her, as for Longhurst (2001), is "the affect or feeling of anxiety, loathing and disgust that the subject has in encountering certain matter, images, fantasies—the horrible to which it can only respond with aversion, nausea, and distraction" (p. 28). The abject evokes fear and disgust because it exposes the border between the self and other; the abject threatens to disband the subject by melting the border.

For Weiss, his wife's body with only one breast renders her body abject and non-normal, and thus asexual and "unattractive." His hope that his wife's body might even be more beautiful after the surgery ("...it was OK to hope to have an even more beautiful and happy wife at the end of the treatments and surgery") might be partially seen to emerge from this sense of threat of the 'disfigured 'borders'/contours of his wife's body threatening his ability to relate to her sexually. Her beauty mattered to his sense of who he was, and to his sense of continued maleness ("I wanted to see pictures of young, beautiful women with reconstructed breasts because my wife is young and beautiful. I explained that if the new breasts weren't going to be beautiful, then I wanted to start coming to grips with that now and not be disappointed later"). Probing the metaprescriptive associations around the amputated body suddenly casts light on the assembled equations between 'two breasts, attractive, and sexual' and the polarities inherent in them. At this point, the amputated body is not so much about losing a part to save the whole, as much as it is about losing a part and replacing it to appear normal (to please men, not look 'deviant'; c.f. Goffman, 1967).

If '*chemotherapy*' raised issues of language –its 'doubleness,' the supremacy of the denotative in scientific discourse, '*amputation*' raises issues of the social construction of the norm and notions of the normal. A norm is based on statistical supremacy and it is worth pondering why exactly a woman needs two breasts. We have two kidneys, silently there, the other taking over if one is lost; but the visibility of breasts complicates the 'norm' in this case; it generates beauty myths and 'becomes' or is perhaps 'constructed' into being the site of sexual arousal. The essential function of lactation of offspring is completely overlooked till the moment she gives birth.

Prostheses

Issues of amputation are, of course, intimately linked to concerns about reconstruction, and there are, as with the previous metaprescriptive utterances, some very complex views about this as well. The polarities around prosthesis play on absent (non-normal) breasts versus those bodies that are "normal," polarities that exert pressure on women to present their public, body images (Grosz 1994) in specific ways. Lorde (1980) critiques prosthesis on four bases: that women who opt for it risk losing self-awareness and feminist visibility (particular statements that the bodies of a single-breasted or no-breasted woman can make), that this choice is complicit in the patriarchal culture's sexist politics of appearance; that there are dangers in reconstructive surgery, since cancerous breast tissue can form and be hidden under implants; and reconstructed women cannot be effective breast cancer activists. Lorde concludes that the cultural emphasis upon surgical prosthesis serves a "way of avoiding having women come to terms with their own pain and loss, and thereby, with their own strength" (p. 49), and swears to either love my body one-breasted now, or remain forever alien to myself (p.44). Since "self-alienation is unthinkable, self-acceptance becomes essential" I refuse to have my scars hidden or trivialized behind lambswool or silicone gel" (p.60).

Some of these views find echoes in the following narrative of a young college student struggling with whether or not to have her body reconstructed:

Tania: Chapter 13, a 21 year old college student:

From: *Not just one in eight: stories of breast cancer survivors and their families*

Initially, I didn't think about the aesthetics when I lost my breast. I thought "In order for me to live, it has to go! Wearing a prosthesis or having reconstruction didn't occur to me until I was recovering and was visited by a Reach for Recovery volunteer. She brought me this silly little stocking thing with stuffing in it. I became angry, because it was as though everyone would be much happier if I "had a booby." It wasn't my fault I had lost my breast, and I didn't feel there should be any shame involved. At that point, I became adamantly against reconstruction.

I didn't wear a prosthesis for three years because I wanted to become comfortable with who I was, having only one breast. I'm a lesbian and for me having only one breast was like "coming out" all over again. When is it a good time to tell someone? Do I have to tell them? Is it an issue or non-issue? May be if every woman opted not to have reconstruction, everyone would grow more uncomfortable with it. I know its difficult to function in society without breasts but if we all said its not our fault and we were comfortable with it, people would have no choice. A classmate who didn't know me well one day asked if I stuff my bra. When I told her I had lost a breast to cancer, she felt terrible. In a way I was glad she was honest.

Most days I feel comfortable not wearing a prosthesis but it is easier having two breasts, because then it is a non-issue. I wore my prosthesis to a job interview. Why? Because I didn't want to go through potential discrimination. If I don't wear a prosthesis to work I wear baggy shirts, simply because I don't want to deal with it. I like having the option. Sometimes though I do think about reconstruction, particularly when my clothes don't hang right. But those days are far and few between. I am glad I made the decision I did. In Stages, Lisa's therapist asks her whether she will wear a prosthesis when school starts. She replies, "No, No prosthesis, and no bra and I'm going to wear something tight." I did that sometimes just to see the kinds of reactions I would get from people.

I was fired as a camp counselor because I had only one breast. When the director found out, he asked me what would I tell the girls when were showering together. I told him I would answer their questions and educate them. Shortly thereafter I was fired with full severance. Was the bottom line what would the children think? What impact would that have on their parents? Or was it because I was gay? I was discriminated against, but I've chosen not to think about it in those terms. (p, 229-230)

While Tania above does not, like Lorde, articulate her desire to be adamantly single-breasted—she is after all only 21 at the time of this narrative—she does, like Stacey earlier, wrestle with her altered identity. Her body image (Grosz 1994, 1995) has changed and as she points out, she didn't wear a prosthesis for three years because she wanted to become comfortable with her altered body. Her statement about 'coming out' all over again in the light of her surgery underscores the agency with which she both confidently speaks of both her body and her sexuality. The notion of the abject body that we saw earlier in relation to Weiss's desire for his wife's body to have both breasts applies in this present context too, albeit differently. In the current case, Tania's (and Lourde's) desire to come to terms with their different bodies speaks of their resisting what McClintock (1995) refers to as the "psychic processes of abjection" (fetishism, disavowal, the uncanny) to take up abjections as political stands that allows them to speak back to the metaprescriptive associations around amputated body-parts. McClintock distinguishes between various kinds of abjections thus:

With respect to abjection, distinction can be made, for example, between abject objects (the clitoris, domestic dirt, menstrual blood), and abject states (bulimia, the masturbatory imagination, hysteria), which are not the same as abject zones (the Israeli Occupied Territories, prisons, battered women's shelters). Socially appointed agents of abjection (soldiers, domestic workers,

nurses) are not the same as socially abjected (fetishism, disavowal, the uncanny) are not the same as political processes of abjection (ethnic genocide, mass removals, prostitute 'clean ups'; McClintock 1995, p.72)

The abject, then, is intimately tied to powers of horror (Kristeva 1982), taboos, collective ideas about repulsion, purity, and the sacred and the polarities accompanying them. In light of the present discussion, abject bodies may be simultaneously sites of internalized male gazes, where Tania's concerns about clothes hanging well for interviews dominate, as well as sites of agency, where she counters being discriminated against for being single-breasted. Abjection, then, as Young (1990) points out, needs to be understood in terms of "understanding of a body aesthetic that defines some groups and ugly or fearsome and produces aversive reactions in relation to members of those groups" (p. 142).

Moving into a wider realm

Susan Sontag points out a crucial relation between illness and language, namely that illness in itself is a non-discursive condition, but the language by which that experience of illness gets discoursed sediment into prescribed ways of thinking especially by societal and biomedical discourses. She says:

[I]llness is not a metaphor, and ... the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking. Yet it is hardly possible to take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped (p.3)

This idea that body breakdowns happen regardless of the language used to describe it is crucial here, and not just because it counters some strains of [poststructuralist] thinking that insists that experiences emerge only through language, but because of the tensions it points to between illness as experience and illness narratives being all about biomedical and societal discourses. There is a slippage here between the ailing condition and the ways in which it gets languaged. The experience of falling ill or having one's body breakdown precedes the languaging of it, and the only way an ailing person has to speak of her condition is through colonizing medical tropes. These societal and medical tropes are hard to defy since they assume vitalities and legitimacies and are reproduced all the time, but, as this paper points out, the accounts of women with breast cancer show how they appropriate metaprescribed utterances to speak back.

However, the texting of these issues are full of tensions, and it is important that we address them. While the recording of such voices is crucial (Duchan and Kovarsky 2005), equally crucial is the need to be vigilant that experiences do not get settled, simplified and frozen. A big challenge, here, then, is the attempt to carve out textual and discursive spaces that will the bodily epistemology of knowledge that conveys the agonies of embodied experience even as it interrogates the categories and discourses within which we understand that experience. The present discussion of 'ailments' and 'disabilities' is to be understood in light of attempting to create this precarious space that has both articulation and questioning as its modus operandi. These spillages around *chemotherapy*, *amputation* and *prosthesis* point at once to those Ricouean moments where in our experience "living expression states living existence...where our movement up the entropic slope of language encounters the movement by which we come back this side of the distinctions between actuality, action, production, motion" (Ricouer 1977). The present focus on both language and lived bodies points an oppositional tension but also a dynamic connection between the metaprescriptive utterances (such as the above) being both tropological figures, as well having material existences, of both generalization and specificity, of aesthetics and pragmatics, of abjectness and attractiveness, of deviance and normalcy. Breasts, cancer, bodies, then, are not just about denotative, medicalized facts, but have narrative and interpretive dimensions around them (Gee 1990; Kramsch 2000; Shradakova and Pavlenko 2004) that given particular bodily experiences demand alternate languaging that contest the colonizing bio-medical tropes. This paper is a step in that direction.

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Endnotes

ⁱ Sontag's criticism of the dehumanizing tropes of bio-medical discourses influenced scholars to assume post-modern orientations to bodies. From a sociological point of view, Jackie Stacey (1997), for instance, writes of postmodern approaches to cancer (in *Teratologies: A cultural study of cancer*); situated in philosophy, Margit Shildrik's (1997) *Leaky bodies and boundaries* assumes a postmodern ethic. Lorde's emphasis on difference and her views of gender, race, sexual orientation have informed feminist disability researchers such as Garland Thomson's *Extraordinary bodies* (1997). Assuming a cultural studies orientation, Tanner's writing speaks of a range of body-related issues including objects triggering grief, public gazes by which women's body parts are held, and our readings of photographs of terminally ill people.

ⁱⁱ See also Blommaert 1999, Anthonissen and Blommaert 2007, Wodak 2001, Reisigl and Wodak 2001, Kramsch 2005 for powerful accounts of connections between language/utterances and ideologies).

ⁱⁱⁱ But this relatively new construction of the "medically literate patient" means not a demise of the dominance of medical tropes but only that this more recent construction now runs parallel to medical tropes.

^{iv} As Lyotard points out:

The relation of knowledge is not articulated in terms of the realization of the life of the spirit or the emancipation of the humanity, but in terms of the users of a complex conceptual and material machinery and those who benefit from its performance capabilities. They have at their disposal no metalanguage or metanarrative in which to formulate the final goal and correct use of the machinery. But they do have brainstorming to improve its performance (Lyotard, 1984, p.52).

^v One good example of this is Derrida's notion of viewing all language use, including speaking, as writing, and in so doing produces a new concept of writing.