THE PERSONAL IS POLITICAL IS ETHICAL:
EXPERIENTIAL REVALUATION AND EMBODIED WITNESSING
IN ILLNESS NARRATIVES

by

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Abstract

Feminist praxis prioritizes and values marginalized experiences—with particular emphasis on those mediated by gender—as a strategy to counter culturally dominant stories, theories and practices that support oppressive social forces and as a means through which marginalized folks, especially women, can affirm their identities. The struggles over identity politics have served to broaden the range of marginalized experiences to include those of people oppressed by gender, race, class, sexuality, and, more recently, disability and illness. Experiential narratives of illness introduce unique elements to the feminist project, because, unlike other categories of oppression (with the exception of disability), illness cannot be easily imbued with experiential value, since its manifestations may cause discomfort, pain and suffering. By revaluing illness experiences, these narratives challenge social and cultural contexts—including other narratives—that devalue bodies and physical vulnerability. This devaluation of bodies extends to theories that describe female, coloured, poor and queer folks as more determined by bodily processes and as physiologically and anatomically abnormal in comparison to higher-class white, heterosexual, non-disabled, and non-ill men.

As embodied testimonies, illness narratives introduce reciprocal responsibilities: ill narrators should teach others about suffering by bearing witness to illness, and witnesses should receive embodied testimonies and continue the work of testimony by bearing witness to others. The relationship between ill narrator and witness, however, may be compromised and corrupted by oppressive forces threatening the ill narrator's ability to bear witness and the reader's or listener's ability to receive and continue the testimony.

Through analyses of three illness narratives—by Arthur Frank, Audre Lorde, and Barbara Rosenblum and Sandra Butler—juxtaposed with my narrative of my mother's experiences of breast cancer as a working-class, Asian immigrant woman with limited facility in the English language, I examine what illness experiences reveal about the conditions necessary for effective embodied testimony. Accepting the responsibility for receiving and continuing the work of my mother's testimony, I must, as a daughter and pharmacist, acknowledge my own bodily vulnerabilities. Only by being ethical listeners can we become effective witnesses for stories by ill narrators.

Dedication

In Memory of My Mother

Mimie Wong Chow

and

For My Father

Yiu Sun Chow

Quotation

Believer I am, but admit it:

       words will not cure everything.

Breathless unless in the mouth,

       on a page, they are crushed black spiders.

They have nothing to do with the details

       that make a life.

Every language is different and none exact.

       Karen Connelly
       The Small Words in My Body

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Chapter I

Methodological Gaze: Through the Personal is Political Lens

A. Origins and Transformations of 'the Personal is Political' Strategy

Arising from the 1970s North American feminist movement whose theorists, artists, and activists linked socio-political oppressive structures to the everyday, intimate exploitation of women, "the personal is political" phrase serves as a galvanizing and powerful expression for feminist politics (Alcoff and Gray-Rosendale; Bannerji, "But Who"; Fleischman; Ginzberg; hooks, Talking Back; Lorde, Cancer; Lorde, Sister Outsider). This phrase reconceptualized women's private, everyday experiences and served as a rallying cry for their struggles against personal and political injustices. How women are systematically treated in society impacts upon their treatment within the home, their intimate relations with men, women and children, and their self-esteem. In turn, intimate and private relationships inform and shape social behaviour and expectations. By

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invoking the phrase "the personal is political," feminists challenged the boundaries that regulated public and private spheres, offering political analyses of the power relations in domestic realms and in interpersonal relationships, and of the movement of power between social and intimate spaces.

The effect of such a phrase could be viewed as two-fold: it served to politicize the personal, and personalize the political. In the first move, personal realms were exposed and strategically brought into political and public arenas. Women became politicized as women through their experiences of sexism within social justice and anti-war movements (Echols; Ross). Through these movements, women connected with each other and shared their analyses of how their vital and mundane everyday work within these social movements often went unnoticed. They linked their overlooked political contributions within these groups to their social and economical locations as women. Through consciousness-raising groups, through analyzing and giving priority to what they deemed personal and private, women voiced their experiences to other women. They validated and affirmed each other's experiences: they could say what they felt, what they thought. Women created their own arenas to discuss how everyday experiences fit into or disappear from social, economic and political spheres, and struggled to obtain recognition for the work they performed within homes. Demanding financial compensation for domestic labour, women argued that their work within homes supported the public spheres of paid labour: women's organizing of household budgets, cleaning, and cooking, enabled men to contribute to the paid work force.

In a counter-flow—that is, the personalization of the political—conceptualizations of political arenas expanded to include personal issues in private spheres. In the 1970s,

socialist and Marxist feminists argued that unacknowledged labour within the home contributed to the devaluation of women's work in the paid labour force (Rosaldo; Sacks). Because women's housework was not seen as work but as familial devotion or acts of love, their work was deemed inconsequential to economical analyses. Women's work outside the home was underpaid, since it was assumed that men were the primary wage-earners in families, while women worked only to supplement their husband's income or out of passion for their jobs. This devaluation is evident in the "feminization" of labour, where work once performed by men is now done increasingly by women—especially, women of colour in economically-poor countries—since women may be more easily exploited than men in local and international economies of labour and capital (Mies). Women's paid work within public spheres, then, is adversely affected by their unpaid, private labour within homes. A struggle for equitable wages must include a revaluation of housework and an incorporation of that labour into the waged economy. Women in the paid workforce, socialist and Marxist feminists proposed, should examine their private labour and roles within families, and use this "personal" as a starting point for their political struggles for wage equity.

Feminists borrowed tactics and strategies of recent political phenomena within and beyond North America in the late 1960s and early 1970s: the Civil Rights and Black Power movements; Marxist and leftist liberation struggles; and anti-Vietnam-war demonstrations. The feminist phrase "the personal is political" arose out of this historical climate to challenge circumscribed boundaries of what we envision as revolutionary, as worthy of political analyses. For feminists, a revolution begins with the self. Feminism and its theories and strategies, including "the personal is political," served to critique

interlocking systems of public and private oppressions with an initial and continued emphasis on gender.

Since being coined as a phrase, "the personal is political" has been a hardy staple for feminist sustenance, causing a historical upheaval of what is considered "personal" and renegotiating what constitutes "political." Its familiarity to activists and academics, along with its appeal in popular culture, has rendered it a paradoxical phrase: emptied of meaning yet semantically stuffed. "The personal is political" has come to mean everything, and, hence nothing. When one wants to draw attention to and buttress one's opinion or position, one can invoke "the personal is political" stance. It is used as a general statement of defiance, wielded against dissent or argument. Part of the imported confusion may be attributed to the rise of identity politics.

During the academic exploration of identity politics in the 1980s, "the personal is political" cry was issued in part as an ontological consolidation of experience and theory (Alcoff and Gray-Rosendale; Fleischman). By stating "the personal" in the form of "I am X," where X represents marginalized location(s) such as "Asian" or "lesbian living with disabilities," one presumed a political stance. Saying, "I am X," called upon experiential histories of oppression with which others were presumed to be familiar. Identification of one's self as a member of a historically marginalized group(s) conjured histories of oppression as well as resistance, marked one as a former victim and conscientious survivor. Identity politics in the 1980s expanded "the personal is political" to approximate the idea that, "the personal is political, and I am X; therefore, I am political." This extended association resulted in a problematic blanket invocation: by stating one's identities, the politics of one's various locations were assumed to surface unquestionably.

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To name one's identities became shorthand for explicating one's political views. Along this vein, "the personal is political" became laden with personal details, oftentimes in place, and to the detriment, of political analysis and discussion. In addition, "the personal is political" was sometimes employed as a conversational preface, where personal experience appeared unanchored to history, set adrift from the politics of place and time (hooks, Talking Back).

Accompanying this post-1970s shift of "the personal is political" within the sphere of identity politics, interest in personal narratives and the role of experience arose due to a proliferation of narratives by marginalized peoples asserting their positions within and beyond academic realms (Fleischman). For many, the possession of marginalized personal experience translated into a calling card permitting entry through political, economical, and academic doors. Post-structuralism, feminism, multiculturalism, and a general academic suspicion of empiricism combined with the sociopolitical gains of marginalized peoples to foster an environment that contested hegemonic structures of knowledge, while simultaneously accepting marginalized experiences (Gever; Fleischman; Narayan). Those historically excluded from knowledge production were perceived as the ones who would be able to fill in the gaps or complete the picture of knowledge with their personal experiences. However, to perceive knowledge as merely incomplete structures a problematic solution. If we regard knowledge as incomplete, we will endeavour only to discern and add missing details to an existing epistemic system and not challenge the system itself. In this search for details, then, marginalized personal experiences may be used as raw materials to enrich old theories and prop up dominant knowledge systems.

When we limit our view to existing dominant systems, we overlook the possibility that so-called "missing details" may already exist in other knowledge systems.

Marginalized experiences, thus, run the risk of appropriation in dominant systems of knowledge, and the folks who offer these experiences may become exploited. Is post-colonialism just a revision of asymmetrical power relations where exploitation has extended from physical flesh to the intellectual appropriation of marginalized folks? Can marginalized experience be anything but marginalized? To relocate marginalized experience and oppositional forms of knowledge, Patricia Hill Collins elucidates the elements required for a black feminist epistemology. In her examination of black feminist thought, Collins argues that black women communicate and affirm their experiences and values amongst themselves through verbal processes such as call-and-response, through the blues music, and through black womanist ethics and consciousness. Black women are capable of making and validating knowledge claims; that is, what they know is not divorced from who knows. Community knowledge supports individual knowledge, especially if it opposes dominant forms of knowledge, which are often reinforced as common sense. For example, contrary to the dominant myths of blackness and violence, the reality for black folks was such that the racial violence of white folks cultivated a fear of whiteness (Davis; hooks, Black Looks). Speaking from personal experience—and its epistemological rendition, feminist standpoint theory—continues to be a vital strategy in

black, white, and third world[1] feminist politics and theory. Currently, "the personal is political" appears in academic discussions about identity politics and within feminist critiques of experiential essentialism.

B. The Problem and Value of Experience: Personalized Scholarship and Representation

In feminist academic arenas, Suzanne Fleischman contends, "the personal is political" strategy transformed into "the personal is theoretical" academic stance beginning in the 1980s. According to Fleischman, "the personal is political" strategy forged a new genre of academic work called, "personalized scholarship," which, in turn, contributed to the academic discourse of identity politics (1006). "The personal is political"—or its academic incarnation, "the personal is theoretical"—strategy continues to be a methodological gateway through which personal experience enters mainstream and academic discourse. Personalized scholarship expanded the parameters of experiential

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[1] I use the term, "third world," to apply to those feminists whose politics includes a gendered analysis of global economies, and whose feminist vision encompasses the effects of colonization and migration on women and political change. In the anthology, Third World Women and the Politics of Feminism, Chandra Mohanty deliberately uses the term "third world" to refer to "the colonized, neo-colonized or decolonized countries (of Asia, Africa, and Latin America) whose economic and political structures have been deformed within the colonial process, and to black, Asian, Latino, and indigenous peoples in North America, Europe, and Australia" (ix). Mohanty, Russo, and Torres propose that the term "third world" be adopted to acknowledge the histories of structural dominance between the first and third worlds, and to situate the historical and contemporary anti-racist and anti-imperialist struggles against such dominance (x). Further, Mohanty positions third world feminist politics in opposition to problematic notions such as: "third world" in international development work; "universal sisterhood" in North American white feminist theories; and "third world women" in feminist analyses and international policies. The politics of third world feminism connotes a consciousness of colonial and neo-colonial migrations and dislocations, local and global economic disparities, and histories of resistance (1-47).

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writing beyond memoirs and autobiographies, and contributed to a revaluation of memoirs and autobiographies as texts of potential theoretical merit. Women's diaries, domestic instruction manuals, and, more recently, illness memoirs came to be regarded as artefacts conducive to analyses and theorizing. Experiential analysis became a methodological possibility.

In personalized scholarship, academic writers often locate themselves and offer descriptive pictures of their particular circumstances and perspectives. They may use prefaces such as "speaking as X" or "living as Y" to announce their experiential knowledge and embodied positions. For example, by using the preface "speaking as a woman of colour in the academy" or "living as a non-disabled immigrant," I may present what I claim to know as what you not only do not, but also cannot, know. In the "speaking as X" strategy, I may also claim that what you think you know does not constitute knowledge. I locate my knowledge as you locate yours. Or alternatively, by using the "speaking as X" preface, I may demarcate what and who is included. Words may be directed to a specific audience that may share my experiences and locations. In feminist realms, women began by speaking to each other, directing their speech to other women. However, the category of "woman," as some of the works and speeches revealed, was presumed to contain primarily white, middle-class, heterosexual and non-disabled women. Women of colour, women living with disabilities, poor women, and lesbians criticized the category of "woman" and the erasure of differences in the yearnings for an unproblematic "sisterhood." For these women, their experiences occurred at the interstices of various marginalized and privileged locations. They claimed that women's experiences emerged from multiple locations because the category of "woman" is not a unitary or fixed locus.

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The proliferation of their voices and concerns emphasized the importance of different identities to feminist analyses, and expanded "the personal is political" strategy into an examination of identity politics.

In the "speaking as X" strategy, one can include and exclude members of one's audience, drawing some in, while keeping others at bay, for various intended and unintended reasons. To specify one's locations is to acknowledge historical circumstances and announce a point of narrative departure and arrival, clearing the way for others to follow with their own historical specificity, their own social and historical relations, and their own place within global and local politics. Hence, the "speaking as X" stance encourages listeners and readers to ponder the speaker's location as a point of reference or comparison. The ability to include and exclude rests on an embedded assumption that when one "speaks as X" or inhabits a position of representativity, whatever is derived from that position—what utterances and conveyances, what experiential elements—is particular and, to a certain extent, beyond the judgmental scrutiny of many who do not inhabit that position. Experience counts: if you live it, you know it. But what do you know? What counts as experience? The invocation of experience, with its accompanying "speaking as X" preface, serves as a conduit through which "the personal is political" transforms into "the personal is theoretical" in academia. Personalized scholarship relies upon the acceptance, application, and transformation of experiential accounts into theory. Through investigating and debating the quality of experiential accounts, feminist theorists stretched "the personal is political" against the rigors of academic theoretical frameworks.

Since the 1980s, the use of experience in feminist theory and politics has come under criticism by feminists who argue against its essentialist leanings. Yet, essentialist

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strands of experience buttressed feminist and identity politics. Activists within the women's health and disability movements transformed their common experiential realities into forms of embodied and lay expertise to counter the biomedical model of health. They problematized the passive role of patients within the biomedical system and the subsequent one-way transmission of knowledge from medical expert to pliable patient (Batt; Lorde, Cancer; Sherwin). The 1976 publication of the women's health guide, *Our Bodies, Ourselves: A Book By and For Women,* by the Boston Women's Health Book Collective, shifted the locus of expertise in women's bodies from the androcentric biomedical system to women's own experience of health and illness. Along a more essentialist vein, cultural and radical feminists argued that women, by virtue of their maternal instincts and reproductive role, possessed superior forms of relational skills and social consciousness. Maternal feminist ideologies fuelled the 1970s and 1980s peace and anti-nuclear movements, where women claimed that there would be no wars if women ran the government and led countries. By asserting that certain forms of knowledge could only be accessed through lived experiences and embodied realities, women created discursive and political spaces that excluded and challenged male-dominated or androcentric opinions and notions of professional expertise.

The strength of experiential narratives and the representational power of the "speaking as X" form afforded many marginalized folks unprecedented discursive space and arenas for speech. Critics of the essentialist use of experience in feminist theory and pedagogy, including historian Joan W. Scott, argue that the project of narrating experience is often mistaken for a statement of facts or truths, rather than a discursive and linguistic event. Scott notes that experience is often problematically conceived of as

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evidentiary—a "foundational concept" —and thus possesses explanatory force in the construction of history. In other words, if experience is regarded as evidence for historical claims, then experience forecloses any discussion or inquiries. When perceived as historical evidence, experience becomes an irrefutable artefact. Scott argues against such an interpretation and use of experience, proposing that "experience [is] at once always already an interpretation and is in need of interpretation; what counts as experience is neither self-evident nor straightforward" (37). In effect, Scott calls for a more dynamic and fluid view of experience, emphasizing discursive linguistic elements in structuring our experiences, whose articulation in turn shape our identities and social consciousness .

Although feminists generally agree that essentialist viewpoints are problematic, some feminists have taken issue with Scott's argument, pointing out the fallacy of reducing experience to a wholly discursive phenomenon (Downs; Stone-Mediatore). Laura Lee Downs questions the value of Scott's view in light of the embodied realities of sexualized violence and the physical suffering incumbent upon those whose material existence is dictated by structural misallocations of resources. Where do women's bodies fit in such a discursive and disembodied model of experience? Other feminists contend that poststructuralist conceptions of experience in the vein of Scott's may discredit and deny one of the few avenues through which marginalized folks may articulate their realities (Bordo; hooks, Teaching; Sandoval; Stone-Mediatore). "[A] totalizing critique of 'subjectivity, essence, and identity' can seem very threatening to marginalized groups," writes bell hooks, "for whom it has been an active gesture of political resistance to name one's identity as part of the struggle to challenge domination" (Teaching 78).

Arguments in favour of experiential accounts in scholarship note the importance of self-representation. Experience-oriented texts provide vital and necessary tensions as they simultaneously resist and engage hegemonic discourses. For marginalized folks, the act of writing and articulating their experiences offers control over their subjectivity and locates them as producers of knowledge (Stone-Mediatore 123-24). In response to Scott's critique of experience, Shari Stone-Mediatore examines Chandra Mohanty's conception of experience and the role experiential accounts play in third world feminists' praxis and their efforts to revalue and reconceptualize experience (122). Stone-Mediatore concurs with Mohanty, who argues that narratives of marginalized experience that historicize experience and struggles can contribute to a community consciousness, and challenge the dichotomy between private and public life, between local and global politics, labour and capital . Drawing on Mohanty's and other third world feminists' views of experience-oriented texts, Stone-Mediatore calls for us to regard experience as that which facilitates oppositional discourses and contains tensions and contradictions "between ideologically constituted perceptions of the world and reactions to these images endured on multiple psychological and bodily levels" . Through narrating and renarrating experiential texts, we may develop what Mohanty calls an "oppositional consciousness" that uses lived knowledge to ground a radical rewriting of our identities (Mohanty in Stone-Mediatore 123, 25). In addition, Stone-Mediatore challenges readers of experience-oriented texts not to reduce those experiences to empirical evidence or purely discursive constructions; rather, we should use these texts to discern the contradictions in our own experiences, and to enlighten our own oppositional projects (130).

Feminists inhabit complex and multiple locations of oppression and privilege. We write our experiences and read others' experiential narratives. The acts of remembering, narrating and reading cohere reflexively, enabling us to contrast and compare our experiences with others and, in so doing, transform our experiences (Stone-Mediatore 125). When we read others' standpoints, we are privy to what "[Sandra] Harding calls, 'thinking from the standpoint of others' lives'; that is, interpreting the world in view of the insights of those who have struggled against oppression or exploitation" (Stone-Mediatore 129). But if we are privy to others' standpoints, may we speak for them, or in their place?

The problem of speaking for others, asserts Linda Alcoff, can be reframed as the problem of speaking. Alcoff proposes that when we speak, we are never just speaking for ourselves, since one's membership in social groups may be tenuous and contingent. Identifying herself as Panamanian-American, and of mixed ethnicity and race, Alcoff observes that, "The criterion of group identity leaves many unanswered questions for a person such as myself, since I have membership in many conflicting groups but my membership in all of them is problematic" (Alcoff 8). For those of us who belong in seemingly dichotomous identity categories—such as Asian and white, bisexual, transgendered, or intersexed—the elucidation of "X" when one "speaks as X" is not straightforward or easy. We must constantly choose and refine our "X" or identity category, infusing it with whatever complexities moments of group alliance may demand. A problem of speaking, then, involves the assumption that well-defined parameters exist around identity categories when, in fact, identity categories are increasingly porous. Thus, the initial problem with "speaking as X" is self-identification: "which X am I at this moment?" Another problem with speaking is that audience members usually identify or

categorize the speaker, oftentimes receiving her or his experience as representative of, or contextualized within or against, particular social groupings. If I were to speak as a queer Asian woman, my location may be received as representative of Asians (by non-Asian queers), or as against the category of Asian (by homophobic Asians). This problem with speaking concerns audience reception: being externally identified by audience members who may or may not comprehend the complexity of the speaker's location, and the intentions behind her or his speech.

Whether self-identified or identified by others, a speaker's representativity is not fixed or static, nor can it be wholly controlled or limited. However, Alcoff does not deny that whatever location a speaker announces may be "epistemically salient" and "discursively dangerous," especially in situations where one speaks for those less privileged, for such speaking may reinforce the oppressive silencing of those for whom we speak . But, as Alcoff observes, "we cannot neatly separate off our mediating praxis that interprets and constructs our experiences from the praxis of others. We are collectively caught in an intricate, delicate web" . To acknowledge the intricate web of privileged and marginalized locations, we should create environments for dialogue, for "speaking with and to" rather than "speaking for" . To reinforce this dialogical environment, Alcoff suggests that we grasp the power dynamics and discursive effects of our speaking by analyzing what compels us to speak, explicitly interrogating the impact of our location on what we say, assuming accountability and responsibility for what we say, and most importantly, evaluating where our "speech goes and what it does there" . Speech—in the form of communicating experiential accounts—possesses the potential to engage people in dialogue. In that engagement, discursive tensions and contradictions disrupt hegemonic

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discourses so that experience transforms within dialogical spaces, and we, in turn, transform. Thus, we want speech to enter dialogical spaces, and once there, we want it to engage as it disrupts.

Arthur Frank also calls for a dialogical interaction between narrators of experiential accounts of illness and their audience in order to make illness narratives more credible to people living with illness and to their caregivers ("Illness"). Specifically, Frank envisions this interaction as "embodied witnessing," where people living with illness and disability give testimony to their experiences of physical suffering and pain, and their audience receives this testimony and then gives witness to others in expanding concentric circles of witnessing (Wounded 142). "Testimony is distinct from other reports," asserts Frank, "because it does not simply affect those who receive it; testimony *implicates* others in what they witness" (Wounded 143; original emphasis). In that implication, those who receive testimony become responsible for what they've witnessed. The value of illness narratives, Frank suggests, lies in their ability to affect the narrator and the readers by creating a relational space—which he calls a "dialogical space"—between embodied witness and audience ("Illness"). Frank qualifies "dialogical spaces" by how well the narrator can disrupt the illness narrative, shifting the narrator's usual unitary, monological consciousness to that of a destabilized (e.g. through surprise or unexpected discovery), dialogical consciousness that reveals the influence of other consciousnesses . The narrator's destabilized consciousness triggers the reader's destabilization by eroding the expected relationship between narrator (active speaker) and reader (passive reception), and thus offers a point of entry for dialogical engagement or polyphony—terms that Frank borrows from the literary critic Mikhail Bakhtin ("Illness" 7, 22). For Frank, dialogical

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engagement sets up a relational space wherein ethical claims can be made in autobiographical illness narratives (to be discussed in chapter 2).

A dialogical space challenges readers to work, to engage in the witnessing of illness; it also refutes the idea of the "authority of experience" (Fuss in hooks, Teaching 81) in its expressed requirement of experiential disruptions and a destabilized narrative consciousness. Dialogical spaces nurture what bell hooks calls the "passion of experience," which she describes as a "passion of remembrance" that encompasses embodied knowledge of suffering and pain, along with its bodily manifestations . Instead of viewing experience as a privileged standpoint where one may claim an authority of experience or a special, exclusive knowledge, hooks shifts the epistemic locus to emphasize bodies and embodied expressions. Bodies are sites of inscribed knowledge and suffering. Physical and psychological proximity to experiential accounts matters. One's visceral distance from sources of knowledge, especially suffering and oppression, affects the complexity and degree of one's passion, as opposed to one's authority (91). Dialogical spaces, thus, encourage an engagement of expressive, passionate bodies. In illness narratives written in the style of Frank's embodied witnessing, the passion of experience drives the narrative even as it disrupts the discursive flow. The passion of experience also sets up the ethical quality of the relational, dialogical space: our impassioned bodies bind us in a mutual responsibility to each other and to the narrative itself. Literary dialogical venues enable relational systems where we may lay the groundwork for ethical and social obligations and responsibilities to people living with illness, whose embodied witnessing of their illnesses destabilize and challenge our consciousness.

C. The Passion of Identity: Identity Politics and Illness Narratives

Personalized scholarship and experiential accounts in general rely on particular rhetorical features and narrative tactics that engage readers and listeners. By their very structure, first-person narratives are stark contrasts to academic writings that rely on "depersonalizing effects" for their authoritative stance and theoretical power (Fleischman 977-81). In her examination of personalized scholarship and the language available to female scholars, Suzanne Fleischman notes that the academic voice employs rhetorical devices and practices that originated in nineteenth century rationalism and empiricism. Linguistic protocols, such as using the passive voice, "backgrounding" writers and foregrounding their generic scholarly persona, and challenging the research instead of the researchers, depersonalize the work, and this, in turn, preserves the reputations of scholars and maintains the sense that scholarly writings represent statements of fact that transcend the transmitter (977-81). These protocols comprise what Fleischman calls the Discourse of Knowledge, which includes the scholarly voice and the scientific voice . Ursula LeGuin proposes that scholarly and scientific voices belong to the "father tongue," which creates distance by separating the subject (writer) and the object (audience), thus preventing or discouraging response; whereas, the "mother tongue" connects with readers, is conversational and expects and elicits response (LeGuin in Fleischman 983). Within the past century, the father tongue has derived discursive muscle from the ever-increasing social and cognitive authority of science and medicine (Wendell, Rejected).

Feminists have historically criticized the artifice of objectivity within academic scholarship. By introducing personalizing effects such as experiential accounts that employ

'I'-statements (Fleischman 983-89) and foreground the narrator's physical and psychological presence, feminists insisted that "the personal is political" belongs in scholarship and possesses theoretical weight. However, Fleischman reflects, 'I'-statements do not necessarily engage in the project of the mother tongue. Sometimes, the use of the pronoun 'I' is part of the persona of the writer—just a pronoun choice without a narrating consciousness that attempts relational engagement (983-89). Or, texts possessing 'I'-statements may focus solely on personal details, where the narrative voice cannot move beyond its own presence to engage with others. Attention to personal experiences, bell hooks warns, may turn "the personal is political" into nothing more than a self-obsessive mantra, if not linked or combined with political endeavours to effect collective change (Talking Back 106). To avoid narcissism, hooks advocates that we locate ourselves in history, using memory and confession as experiential tools to explore our collective reality, so that "[s]torytelling becomes a process of historicization" (110).

While Fleischman offers a primarily gendered analysis of the academic voice, I would argue that personalizing effects within academic writings offer an increasingly "raced," "classed," and "abled" discourse. The names of academics reveal a diversity of gendered and ethno-cultural intellectual presence. For those who recognize such distinctions, some names belong to certain castes or classes in local and global economies of knowledge. More obvious, the insertion of genders (e.g. FTM or female-to-male, transgender, third gender), race, class, disabilities and illness into the academic voice is effected through narrative content. Personal details locate the narrator in body, place and time. Elements of class, colonization and migration surface through the narrative use of slang, dialect, patois, pidgin English, or "proper" Canadian, British, or American English.

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The availability of academic texts in Braille, the organization of note-takers within

academic courses, academic and political support for students with disabilities, disability

studies, and the gradual structural changes within universities and colleges enable people

with disabilities and illnesses to participate within academia and thus strengthen its

intellectual debates.

As a currently non-disabled, and non-ill, queer feminist Asian immigrant, I inhabit

locations of privilege and oppression and am a product of the identity politics of feminist

scholarship and activism. Despite the feminist critiques of identity politics, I remain

indebted to its essentialist strands (even as I note their problematic presence) for affording

me spaces to negotiate my identities. Like bell hooks, I value the passion of experience

and appreciate how my articulation of suffering and pain has transformed my feminist

consciousness. While essentialist ideas can be useful, they can also hinder ethical and

pragmatic action. Uma Narayan argues against the ethically paralyzing effect of cultural

essentialism by asserting that, "culture comprises a cacophony of voices and thus should

be understood as the language of argument about identity" (1036). By reframing cultural

identity as cacophonous, she fragments the assumed unity of cultures and identities.

Narayan's cacophonic cultures and Frank's polyphonic dialogical spaces open the

conceptual possibilities for deconstructing and reconfiguring identities within and through

illness narratives. Illness narratives offer not only a passion of experience, but also a

"passion of identity." By "passion of identity," I mean the relational effects within

dialogical spaces that reshape identities and make links with other people who might be

similarly identified. The passion of identity infuses experiential narratives with ontological

import, especially for those attempting to speak from marginalized locations.

For people living with illness and disability, and other marginalized people, "the personal is political" strategy, with its "speaking as X" structure, commands and demands attention. By locating oneself, the illness narrator prods listeners to engage their identities, their understanding of where they may sit on the continuum of health and illness, birth and death, and thus interact with what is being said or written. Further, to announce one's location is to offer socio-political context, to flush out the presence of those who share your location; thus, summoning others to back up your experiential position. Hence, "the personal is political" strategy also affords its speakers and writers a measure of defence against hostile attacks, especially against what Susan Wendell describes as the social and cognitive authority of medicine (chapter 5). For people living with disability and illness, their experiential realities are usually filtered through and predominantly shaped by the medical model's interpretation of human bodies. Often, medical interpretations serve to invalidate and discount a person's experience of illness and disability if their symptoms do not match any known diagnosis, or if their bodies do not respond to treatments as expected. In all, this amounts to a "social abandonment" of the person (Wendell, Rejected 129). "The personal is political" strategy of illness narratives counters the authority of the medical model by exposing its cognitive lapses and experiential vacuums.

Autobiographical illness narratives are textual experiential accounts that individually employ "the personal is political." As illness narratives accumulate, we may seek out common themes, observations, and tensions, and generate theories from these commonalities. Individual narratives build upon other illness narratives to create a collection of works that permits analyses within the framework of "the personal is theoretical." Taken collectively, illness narratives support and advance personalized

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scholarship within academia, and introduce sufficient discursive instability to challenge hegemonic or master narratives and our overtly or covertly prescribed roles within them. My experiential account of my mother's illness with breast cancer serves as a dialogical response to the illness narratives by Sandra Butler and Barbara Rosenblum, Arthur Frank (At the Will), and Audre Lorde (Cancer). Through the passion of identity in experience-oriented narration, I may discern and elucidate my responsibilities and ethical obligations to these illness narratives and to my mother's memory.

D. My Personal, Political, and Theoretical: Narrating My Mother's Illness

Within "the personal is political" strategy of illness narratives, the "personal" may consist of a web of various people whose lives one touches, or with whom one's experiential accounts intersect. In telling about oneself, stories about others also surface, and in that surfacing, an ethics of revealing must be considered. One must weigh where one's "personal" ends, and where another's "personal" begins, even as one's "personal" overlaps and co-constitute others' "personals." As illness stories proliferate and as feminists rally for the inclusion of their experiential realities in struggles for social justice, we must consider the ethics of what we reveal when we proclaim, "the personal is political." Since my "personal is political" account directly involves my mother, and other members of my family by association, the ethical interactions within families must be considered; especially when a daughter chooses to write about her "personal" in order to make it political and theoretical.

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Writing about my mother is fraught with daughterly[2] and cultural conflicts. Before her illness and during, my mother was a very private person. My sense is that she felt: the less people knew, the less they could hurt her. Along with her guarded privacy, she did not want to be singled out, did not want to be a problem. Whenever I wanted to ask her doctors or nurses about her treatments, she often said, "Mm ho gum bah-biy." Or, "don't make a fuss." Or, perhaps more accurately, "don't mess it up with your fuss." Her comment to me may be interpreted in many ways: stoic yet respectful resignation to whatever care the doctors and nurses would offer; fear that, as a patient and immigrant unfamiliar with the English language, she would not be treated well by the very people (doctors, nurses, hospital staff) she desperately needed as allies in her illness care; or, sad yet determined independence as a woman struggling with end-stage breast cancer.

Since I am trained as a pharmacist, the possibility that my mother's illness could become worse entered my consciousness largely in the shape of clinical disease progression and the prospect of physical suffering. I believed her sense of helplessness and vulnerability would be ameliorated by knowledge about her condition and by participation in treatment decisions. I was unprepared for her ambivalence toward my questions to her doctors and nurses, my requests for information about her illness and care toward the end-stage of her cancer. I felt as if she "shooed me away" from my dutiful advocacy. In retrospect, I suspect she knew that whatever doctors and nurses could tell her was

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[2] By not using the word, 'filial,' I want to emphasize my gendered location with respect to 'protecting' my mother from people, even relatives, outside the prescribed nucleus of my family. As the eldest and as a daughter, I occupied particular roles: care-giver for my brother, and gate-keeper of information about my mother.

something she would rather not know, and already knew. My mother's ambivalence about medical talk—what the doctors or nurses had to say—caused me to consider whether I had given her enough credit. In the later stages of her illness, there was nothing spectacular or theoretical that medical science could tell her. She would be the one to unfold her body's narrative. All any of us could do was to witness this unfolding. Or had she been the narrator of her body all along, but I had only realized it as she lay dying? Yet, I kept asking the medical staff about her condition and care because I came to regard my questions as evidence (to my mother, father and me) of how much I cared for her despite our estrangement. Not asking was something I could not do. Also, my retrieval of the details of her illness fed our thin conversations, gave us something to talk about. In the end, what mattered was my act of interpreting medical information to her and not the medical information itself.

Part of my thesis will involve an experiential analysis of my mother's illness: to recall what I had witnessed and offer an interpretation alongside the context of other illness narratives and feminism's use of "the personal is political." In the spirit of my mother's memory, "mm ho gum bah-biy" will serve as my methodological guide and directive, moderating and inflecting my feminist endeavour to make the personal political. To respect her privacy in death, to not mess it up with my fuss, I will keep in mind some guiding thoughts, using them as touchstones to consider what to reveal, what to keep off the page.

For families and intimate relationships, Hilde Lindemann Nelson and James Nelson propose an "ethics of the intimate" to supplement general theories of morality and medical ethics. Nelson and Nelson argue that moral principles such as Immanuel Kant's categorical

imperatives, or utilitarian views founded by David Hume, Jeremy Bentham, and John Stuart Mill, cannot encompass the complexity and primacy of the personal points of view so prevalent within families. In the context of familial and intimate relationships, we do not act solely out of duty or universal utility but primarily out of love. Because of love or other emotions such as guilt or resentment that are a part of our families' relational history, we do not abstract situations so that we can, as advocated by general theories of morality, obtain an impartial standpoint and act dispassionately (Nelson and Nelson 55-60). In contrast to general theories of morality and medical ethics, we do not act as individual moral agents within families, but must consider family ties and how our ethical decisions affect each other. To take into account intimate relationships, Nelson and Nelson suggest a morality of intimacy that allows personal points of view and is guided by concepts of collectivity, favouritism, particularity, non-consensuality, and a pre-modern sensibility that acknowledges special duties and claims due to hereditary relations (63-72). Parental, filial, and sibling biases, specific histories of love, betrayal, coercion or guilt, and shared values and expectations are built into and form the essence of familial systems and intimate relationships, and rather than ignore or deny them, Nelson and Nelson advocate that we use them as guiding principles or "stars to steer by" (73-74). Instead of hard and fast rules, instead of moral principles awaiting application, they present their ethics of the intimate as a navigational aid for traversing the ever-changing physical and psychological contours of ongoing stories within families (80-82). They write:

> Much of what happens at any given moment in families takes its
> significance from what has gone before and will go behind. Families are
> often sites whose significance is both 'dense' and 'extended': much of what
> goes on takes place inside a configuration of persons and events that pulls

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together richly developed themes extending across generations. (Nelson and Nelson 80)

An ethics of the intimate, combined with my mother's "mm ho gum bah-biy" directive, provides an ethical framework for my experiential account of my mother's illness. Through this framework, I recognize that my father and brother possess their own perspectives and memories of my mother. In my experiential account, I am narrating my own partial version of my family's ongoing narrative.

My family's migration from Hong Kong to Toronto created our racialized and gendered positions in Canada. I grew up in a Chinese immigrant family whose sense of cultural safety predominantly existed within our home, and within the socio-cultural bubbles that Toronto's various Chinatowns provided. Familial intimacy and loyalty pervaded my childhood home. While these resisted the classist and sexist racism beyond the home, they suffocated me with their justifiable paranoia and daughterly expectations. Like many children of immigrants, I served as the cultural and linguistic interpreter for my parents upon our arrival in Canada. In this thesis, I will attempt the reverse and provide a political and cultural interpretation of my parents' circumstances. In my account of my mother's illness, which features will prove salient to the feminist task of politicizing and theorizing the personal? As I deliberate upon what to reveal about my mother, I must respect my father and brother's past relationships with, and memories of, my mother. To do this, I must reveal the roles I inhabited within my family's relational system and be honest about my estrangement from them. I was never the daughter and sister they expected. If my father and brother were to one day hear of or read this thesis, I hope they would accept this public memory of my mother.

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In writing about my family, I am drawing on the passion of experience and remembrance. My family's history is etched into my bones and features, surfaces in my posture and gait, my expressive gestures and unspoken values. My family's history is ingrained in my childhood memories, remembered glimpses of adolescent rebellion, and recent recollections of an adult daughter. When I write about my family, I call upon embodied memories and gaze through the retrospective and analytical filter of years. Diana Tietjens Meyers, Susan James, and other feminist psychoanalysts regard memories as highly malleable. One's past is not straightforwardly accessible, since we borrow from other existing stories of childhood—such as cultural expectations of mothers and daughters—when we learn or unlearn them. In addition, articulating the past by constructing memories allows one to anchor one's personal identity through "figurative self-definition" (Meyers 241-45). We use available narratives to define and identify ourselves: my story of my mother's illness is co-constructed with narratives that describe and prescribe roles for daughters and mothers within Chinese immigrant and Canadian contexts.

Sexist racism allows me to easily disregard what were my mother's wishes, perceptions, and knowledge. Like many feminists, I grew up admiring the freedom and independence my father represented, in contrast to my mother who was confined to the home to care for my brother and me. Canadian structures that uphold racist xenophobia make it easy for children to dismiss their immigrant mothers and fathers, to forsake their familial and cultural roots. In writing about my family, I may be accused of and responsible for cultural or familial betrayal. Stories about people in marginalized locations, while necessary for enriching available perspectives, may be used to construct them narrowly

and rigidly (Dyck, "Methodology" 33). Even as I attempt to deconstruct existing stereotypes, I may unwittingly contribute to new ones. I believe, however, that the number of circulating narratives is proportional to the opportunities available for the elucidation of differences amongst them.

Sherene Razack warns people of colour about potentially coercive motivations that support their acts of storytelling. She criticizes white colleagues and professors who compel people of colour to tell their experiences of oppression within academic spaces (117). Using their dominant positions to compel confession, these academics seek to authorize or dismiss what is said, and then collect these confessions as raw data for their theories. Yet, if marginalized folks do not tell their experiential accounts, and do not attempt to theorize from their own locations, they may lose opportunities for self-representation, for self-expression. For marginalized folks within academic spaces, as in all spaces, it's the "damned if you do and damned if you don't" dilemma.

These methodological and pedagogical concerns remind me of a conversation with Canadian poet and cultural critic M. Nourbese Philip. During Philip's university course on women and cultural production, I expressed my frustration with feeling ghettoized as a writer. I feared being a cultural token. How would I know if my writing was being judged for its merit, or whether I was being tokenized? I felt trapped within a discursive black hole: whatever I wrote would be sucked of its self-representational force. Why write when one's writing would only be appropriated and categorized? Philip suggested that, rather than worry about being relegated to a cultural token, I should claim the token position as my starting point. In Canada, Philip asserted, we are all tokens. All writers, she argued, are cultural tokens and writing is never judged solely for "its merit" but also for its token

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value—whether to enforce the colonial project, or to sustain myths of migration and settlement. Philip's comments freed me. She helped me realize that my location or footing in a hegemonic, oppressive system acquires less importance if I learn to keep moving, writing, and thinking. In that vein, I would rather be damned as I do.

Chapter II

Three Experiential Narratives of Illness

A. Three Experiential Cancer Narratives: Politicization, Intents, and Discontents

Reflections on illness reveal views on a wide range of topics: cultural identity, treatment modalities, medical and cultural myths, disability rights, racist and heterosexist policies, environmental justice, alternative healing regimens, interpersonal relationship dynamics, and reassessment of one's life due to the threat or approach of death. In The Cancer Journals, poet and black lesbian activist Audre Lorde wrote candidly about breast cancer. At the time, she was one of the first black lesbians to publish contemporary writings about illness, and also one of the first to emphasize the racialized and sexualized representation of breast cancer. Lorde located herself within the feminist movement's twin endeavours of consciousness-raising and breaking silence. In Cancer in Two Voices,

Sandra Butler and Barbara Rosenblum share their experiences of Rosenblum's post-diagnosis life with metastatic breast cancer—how they lived consciously with Rosenblum's cancer as individuals within a lesbian partnership and within their communities of families, friends and colleagues. Since breast cancer is a life-threatening and potentially terminal illness, all three writers consider their mortality, and the possibility of lives cut short by illness.

In <u>At the Will of the Body</u>, Arthur Frank credits social justice movements (e.g. civil rights and women's rights movements), as well as political activism by people living with disabilities, AIDS and cancer, for providing the political analyses and frameworks for his understanding of living with illness. As a medical sociologist, Frank compares and contrasts his two life-threatening illness experiences—sudden heart attack followed soon after by a diagnosis of testicular cancer—and how they differentially affected his identity as a patient within medical contexts, and as a sick person among his family and friends. In 1995, Frank followed up his illness narrative with his book, <u>The Wounded Storyteller</u>—a more theoretical analysis wherein he continues and expands the arguments he set out in his illness narrative. In the later book, he proposes that illness stories represent a form of "embodied witnessing," whereby ill persons give valuable testament to their suffering and call on witnesses to share that testament with others. Frank's premise is that one's wounds confer narrative power, and thus people living with illness, instead of being passive and silent victims, possess a significant and active social role: their wounded bodies reveal truths about our shared human condition of physical and psychological vulnerability (xi-xiii). Although <u>The Wounded Storyteller</u> is not an illness narrative, I will include it in my analysis, since, within its pages, Frank develops and refines ideas that first arose in his

illness narrative: a) illness experiences have personal and social value that merit

recognition; b) wounded bodies possess social agency; and c) people with illness need

voices, and these voices are integral to cultural dialogues about medicine, illness and

vulnerability.

A common element in the aforementioned narratives is the critical analysis of the

confluence of personal and sociopolitical factors in experiences of illness. To varying

degrees, all three writers analyze their identities and the social spaces they inhabit, and

self-consciously identify with their illness.[3] Their considered perspectives offer readers

spaces for reflection and dialogue; in those spaces, readers may consider their own stance

in the act of witnessing or engaging (Frank, "Illness" 22). The writers create meaning out

of their illness experiences by dismantling the historical silence and oppressive fears and

myths that envelop illness and dying, and by challenging the forces that shift these

experiences into primarily medical and private spheres or, especially if one is famous,

publish them as sensationalized and exploitative exposés. Each work resonates with an

explicit intention to make visible particular experiences of marginalization before and

during cancer. Rosenblum writes about the medical professionals who misdiagnosed her

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[3] While my discussion is limited to illness narratives, there were and continue to be recognized
experiential and symptomatic commonalities between illness and disability. Experiential accounts of
chronic illness, specifically cancer, resemble accounts written by people living with disability, because
chronic illness and disability may follow similarly unpredictable courses of stability and/or instability
(depending on the particular illness and disability) without a foreseeable—albeit, often hoped-for—cure or
end (see Wendell, Unhealthy). Despite the commonalities, observes Wendell, people living with "stable
disabilities" (e.g. wheelchair user with amputated lower limbs with no complicating conditions) often
distance themselves from those living with chronic illness (e.g. woman living with relapsing multiple
sclerosis) in order to dissociate themselves from further stigmatization as weak or sick. A hierarchy exists
amongst people with disabilities where the healthy disabled rank above the unhealthy or sick disabled
(Wendell, Unhealthy). Space, however, does not permit me to examine these important distinctions in
detail.

cancer and her ensuing malpractice suit and bittersweet victory against them. The successful lawsuit left Rosenblum and Butler with the sad realization that life can be grotesquely translated into dollars. While Lorde's cancer was not overlooked, she observed that her post-mastectomy body came under a familiar yet different kind of racist and heterosexist scrutiny when health care workers suggested, and at times insisted, that she wear a prosthesis or undergo breast reconstruction with an implant . The economic exploitation of women, Lorde observed, continues in the prosthetics market where breast prostheses are usually inaccurately advertised, of shoddy quality and over-priced. Further, the promotion of breast implants, despite unresolved health concerns about their safety, reveals that women's breasts take precedence over women's lives.

Such a detailed description of sociopolitical location is missing from Arthur Frank's narrative —a retrospective account of his heart attack and subsequent diagnosis with testicular cancer examined through a sociological framework. Although his cancer is gendered, he does not discuss the role of masculinity in his diagnosis and treatment, or the gendered expectations of his illness. Frank does mention, however, his gendered roles as a professor, husband, and father, yet he does this briefly and in passing, reflecting upon his inability to make or honour personal commitments . It would have been interesting if Frank had examined how he is White, male, educated, heterosexual, religious and married in medical and cultural contexts that privilege such subject positions. Because privileged locations are often constructed as the usual or normal vantage points, it is not surprising that Frank does not examine his racialized and classed gender. Along with Lorde, Rosenblum and Butler, Frank does, however, problematize the cultural views of illness and evaluate their impact upon experiences of illness. In so doing, all four authors draw

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attention to the lack of literary and sociopolitical spaces for people living with illness. By contrasting his experiences of two life-threatening illnesses (heart attack and cancer), Frank discerns the cultural myths and stigmas particular to each illness and their effects on his identification with illness, and hence, his illness identity. Instead of other social and political identities, Frank primarily locates himself in the context of illness identities. In this manner, his search for narrative and, consequently, social spaces is similar to Lorde's and Rosenblum and Butler's projects of claiming discursive space from marginalized locations. Through narration, each writer establishes a space for her or his identities within the illness experience.

In this chapter, I will examine the particular illness space each author asserts for his or her narratives. Illness narratives by Lorde, Butler and Rosenblum, and Frank illustrate different illness spaces and the ethical obligations that arise from such spaces of engagement. These narratives embody the feminist commitment to consciousness-raising and breaking silence from marginalized locations: each author attends to political and ethical concerns through careful deliberations about responsibilities to friends, family and others living through similar experiences. They counter master narratives that omit and/or misrepresent the experiences of people living with illness. Their common elements of narrative engagement and political responsibility set the tone for the possibility of dialectical interplay between texts and their readers and writers.

B. Audre Lorde's Warrior Space: Confronting Silences as a Breast Cancer Survivor

The act of breaking silences recurs thematically in Audre Lorde's poetry, essays and speeches. In The Cancer Journals, Lorde contemplated the juxtaposition of silence and voice within the private and personal sphere, and within the public and political arena. The act of publishing her journals—to introduce private reflections into political and public spaces—supports the feminist view that revolutionary insights may be contained in a woman's private musings, a view that still lies at the heart of many contemporary feminist works. Lorde inserted short excerpts of journal entries between longer and more sustained reflections in her narration of the difficulties of being, and being perceived as, a woman with breast cancer. After being pressured to wear a prosthesis, Lorde concluded that women with illnesses and disabilities are often encouraged, if not forced, to hide their scars and any physical evidence of illness and disability in order to appear "normal" or visually pleasing, especially for their husbands. When a woman is compelled to hide her breast amputation, Lorde argues, the enormity of her illness experience—her struggle to survive—is denied and erased by a "physical pretense" that encourages her to dwell on the past (i.e. on the body and breasts she used to have) and to focus on the primarily cosmetic effects of a mastectomy rather than on strategies of recovery from a life-threatening illness . While Lorde takes issue with prostheses, she does allow that women should be able to choose their own method of surviving breast cancer, including the use of prostheses and breast reconstructive surgery. Her main argument is that there should be more choices that are not cosmetic, that do not erase the illness experience, and that fully appreciate breast cancer's threat to a woman's survival.

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Lorde's narrative addresses what I consider a suppressed survivor identity, where illness experience and knowledge are denied not only by what Susan Wendell has called the "cognitive authority of medicine," but also by ongoing oppressive discursive projects that erase female experience and the lived realities of women's bodies. For Lorde, the occasions of her illness and mastectomy reinforce other existing factors that impose silence upon her embodied reality: racism, poverty, sexism, heterosexism and classism. If, as Frank argues, illness merits storytelling because one's wounds confer narrative power (Wounded xi-xiii, 183), then what happens when those wounds are denied? How does one create a story out of an imposed nothingness? To break silences, to conjure visibility from erasure by oppressive forces, Lorde proposes an affirmation of her illness experiences through a conscious acknowledgment of illness by, among other strategic acts, asserting a one-breasted body, and writing and speaking out about the effects of cancer on her life. For many women with breast cancer, asserting one's wounds, one's scars and other physical evidence of illness and suffering amounts to a reclaiming of experience, of one's imperfect and vulnerable body (see also Wendell, Rejected; Wendell, "Unhealthy").[4] This reclamation is an important initial step in the act of confronting the silences that surround

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[4] Some women—including those living with myalgic encephalomyelitis, fibromyalgia, diabetes, and lupus where evidence of illness and disability is not visually obvious—cannot display scars, nor draw visual attention to their injuries in ways that other women with scarred and amputated bodies of illness and disability may (Wendell, Rejected; Wendell, Unhealthy). Rather, they must bring attention to their illness and/or disability experiences through other means: through writing, speaking out, or asserting their identities. In her discussion of whether people living with chronic illnesses should be identified as disabled by people with and without disabilities, Wendell notes that those who may "pass" as non-disabled or whose disabilities are not obvious can be criticized for passing and for not passing (Unhealthy). The choice to pass or not pass is related to a person's need for her or his illness or disability to be recognized and accommodated (Wendell, Unhealthy 28-29). Yet, for some who can pass but choose not to, their illnesses and disabilities may not be believed, or they may be seen to exaggerate or fake their symptoms (29). Similarly, those who can hide their breast cancer behind make-up or breast prostheses but do not may be accused of drawing needless attention to themselves.

and mask illness experiences. As she had affirmed her stigmatized identity as a black lesbian feminist, Lorde considered her post-mastectomy breast cancer survival with an equally self-conscious and conscientious thoughtfulness.

In her conflicted embrace of her one-breasted body, as she peered at the puffy scar running along her skin and contemplated the absence of her breast, Lorde wondered how long it took for the Dahomean girl Amazons, who amputated one breast in order to better wield their bows to shoot arrows, to accept their changed bodies (Cancer 44-45). In her attempts to grieve for her missing breast and to accept her one-breasted chest, Lorde came to identify with Amazon warriors, since she too had to amputate her breast in order to survive, to engage in a fight for her life. Unlike the Reach for Recovery volunteers, who encouraged her to use a prosthesis and cosmetics post-mastectomy to make herself desirable to her presumed husband, the image of the Amazon warrior offered Lorde an alternative role: warrior woman intent on survival. Rather than focus her precious and limited energy on what she regarded as superficial concerns of appearance, Lorde preferred to evaluate the chances of her survival and the strategies involved to enhance those chances.

In the warrior role, Lorde was able to address several troubling issues: (a) the encouraged passivity of women post-mastectomy through a direction of their energies toward appearance rather than a frank acknowledgment of suffering and the need to ensure survival; (b) the lack of support for women, particularly black lesbian feminists, to explore the impact of breast cancer in the context of their lives; (c) the isolation of breast cancer survivors and their further victimization by those who manufacture and promote poor quality breast prostheses and potentially dangerous breast implants; and (d) the

individualization of breast cancer so that the links between environmental pollution, radiation, poverty and chemical additives in foods and the rising incidence of cancer are masked. Hence, the role of the breast cancer survivor as a warrior woman offers women an opportunity to reflect and take active responsibility for their survival. A warrior's stance involves asserting one's sense of self—ascertaining strengths and weaknesses—in order to better confront potential harms and the possibility of pain and death. As a warrior, one must take responsibility for the fight—to evaluate which battles are worthy and then to prepare for conflict and its consequences. As a warrior, one is also seen to be fighting for the greater social good—to serve and protect people and belief systems. A warrior, then, is actively responsible to her or his society and inhabits a valuable social location.

Unlike other battle myths about cancer, Lorde's warrior's battle is not limited to the self against cancer cells, but also the self against those forces that trigger cellular mutation into cancerous cells. Beyond the medical definition of malignancy, cancer is not benign in the sociopolitical sense, since many cancers are preventable. Unrestrictive legislation permitting chemical food additives, toxic waste disposal and radiation technologies have contributed to the rise in incidence of many cancers (Eisenstein; Lorde, Cancer; Steingraber). Policies concerning financial assistance, social housing and occupational standards affect the health of impoverished folks, of whom a disproportionate number are women and people of colour who have been exposed to carcinogenic substances, either through workplaces containing hazardous materials, homes built on former toxic dumps, or foods that contain pesticides and additives (Eisenstein 85-87, 94). Lorde's warrior woman, like Lorde's identification as a black feminist lesbian,

must confront hostile social forces that threaten her survival and the survival of other disenfranchised people. Within this warrior realm, Lorde's survival has a significant social purpose. However, Lorde's social survival was enmeshed with her physical survival, which, post-mastectomy, required an increased vigilance in watching bodily signs and symptoms for malignancy, and in evaluating nutrition and therapies. This heightened awareness of her body, Lorde observed, could lead to obsessive fears about not healing or getting sicker. To grapple with these worrisome concerns, Lorde assumed responsibility for her fears and attempted to find a way to handle them so they would not "bleed off" her strength. Lorde wrote, "I think I find it in work, being its own answer. Not to turn away from fear, but to use it as fuel to help me along the way…[and] to make the jump from impotence to action" (Cancer 54).

In addition to active responsibility, the warrior role allows breast cancer survivors to embrace their changing bodies—as visually evidenced by surgical scars, breast amputation, and hair loss from chemotherapy. A warrior displays her or his scars as proof of battle experience, as testament to having survived what could have killed him or her. When men sport visible wounds, Lorde observed, such as the eye-patch signifying the empty eye socket of Moishe Dayan, then the Prime Minister of Israel, they gain status, since their wounds are interpreted as embodied proof of their acts of bravery (Cancer 60). For many men, their bodies represent a surface upon which life's experience may be revealed and revered. In contrast, women's wounds and amputations serve only to disrupt the sexualized expectations imposed upon their bodies. For breast cancer survivors, their recovery appears integrally linked to making them look better, or to look as if they had never had cancer. Within hospitals, peer support comes in the form of make-up tips and

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information about prostheses promoted then by the American Cancer Society's (ACS)

Reach for Recovery program volunteers, themselves survivors of breast cancer (Lorde,

The Cancer Journals 40-43), and now by ACS's Look Good...Feel Better[5] campaign and

its myriad corporate sponsors within the fashion and cosmetics industry (Ehrenreich,

"Welcome" 45). By claiming a one-breasted warrior woman role, Lorde counters the

aesthetics-focused social support that women encounter when undergoing a mastectomy,

radiation and/or chemotherapy. Her move serves not only to re-prioritize women's

concerns, but also to break down the socially rigid aesthetics of "woman-ness" and

femininity post-mastectomy and post-chemotherapy.

Embracing a body altered by illness necessitates, as Lorde demonstrated, a stalwart

resistance against the oppressive sexist, heterosexist, racist, ableist and classist forces that,

in their promotion of looking good in order to feel good, do not take into account the

problems already inherent in what narrowly counts as "looking good" (White features

accentuated by make-up, moderate-sized breasts, straight white teeth, thin and tall frame,

and heterosexual availability). Even without illness, some women have always inhabited

stigmatized bodies. From her experiences of living with the stigmatized body of a black

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[5] In Canada, *Look Good Feel Better* is a registered trademark of the Canadian Cosmetic, Toiletry and Fragrance Association (CCTFA) Foundation, which publishes an annual supplement by the same name. These supplements are inserted into popular Canadian women's fashion and cosmetics magazines, such as *Canadian Living*, *Flare* and *Chatelaine*, and two health care oriented magazines, the *Canadian Oncology/Nursing Journal*, and the pharmacy trade magazine, *Pharmacy Post* (CCFTA Foundation). Workshops given by volunteers are offered in major cities across Canada. In 2002, the *Look Good Feel Better* program celebrated its tenth anniversary. In a recent article titled, "Welcome to Cancerland," Barbara Ehrenreich, herself a breast cancer survivor, observed that breast cancer, more than any other illness, even AIDS, has garnered immense corporate support, primarily from the fashion and cosmetics industry. As a result, the role of a breast cancer survivor often follows an expected course—which Ehrenreich glibly calls the "career of a cancer survivor"—dominated by what she critically terms "pink kitsch." In other words, the role of the "good survivor" entails partaking in saccharine-sweet fundraisers and displaying a cheery, uncritical volunteerism.

lesbian feminist, Lorde was able to discern the absurdity of masking breast cancer with make-up and prostheses rather than addressing the forces of stigmatization. Women's focus on prostheses and make-up left the forces that stigmatized one-breasted or no-breasted female bodies, and ill and disabled bodies in general, unchecked. In the warrior stance, Lorde advocates an appreciation of bodies marked by experiences of illness and the redirection of energy to oppose those forces that would interfere with such an appreciation. Further, in her warrior stance, she emphasizes the importance of survival and a strategic concentration on the forces that caused her cancer and that continued to threaten her survival: "my scars are an honorable reminder that I may be a casualty in the cosmic war against radiation, animal fat, air pollution, McDonald's hamburgers and Red Dye No. 2, but the fight is still going on, and I am still a part of it" (Lorde, Cancer 60). Warrior women, then, take pride in their stigmatized bodies through their resistance to oppressive and life-threatening forces and their concerted efforts to develop strategies of embodied reclamation and celebration.

Finally, Lorde's insistence on a visual rebellion, wrought by countering the imposed two-breasted norm with her one-breasted warrior woman body, is bolstered by her work as a poet and writer. In her identity as a black lesbian poet, Lorde wrote to transform silences into speech and action, striving to converse with others in the feminist project of sharing insight and working towards coalition politics (Lorde, Cancer 19-21). A visual rebellion, such as countering the imposed aesthetics of post-mastectomy womanhood, is not enough on its own, since stigmatization works on many levels, rendering stigmatized bodies invisible (dismissed and unacknowledged) yet "hypervisible"

(under intense scrutiny and discriminatory judgment).[6] In terms of invisibility, disability

activists and scholars and feminists active in the women's health movement have long

pointed out that people living with illness and disability find themselves easily dismissed

and their needs overlooked. They are excluded from social participation by inaccessible

architectural designs, the lack of adequate and accessible transportation, the physical

demands of fast-paced businesses and workplaces, and the norms of bodily function and

appearance that regulate social interaction (Morris; Silvers, Mahowald and Wasserman;

Wendell, Rejected; Zola). Yet, the presence of people living with disability and illness is

hypervisible because their bodies and behaviour (e.g. psychological disabilities, debilitating

fatigue) stand out, even when they labour to conform to ableist standards. Success lies in

passing as non-disabled or non-ill, since passing grants tangible rewards in terms of

employment and respectful treatment. The mere attempt at passing is also rewarded,

because such attempts uphold discriminatory norms and further the invisibility and

hypervisibility of ill or sick bodies.

   In publicly identifying as a black lesbian poet, Lorde was acutely aware of racist,

sexist, and heterosexist forces that socially and economically discriminated against her

existence, and that rendered her, like other black women, "invisible through the

depersonalization of racism" (Cancer 21). As she had lived before cancer, Lorde chose to

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[6] I first came upon the critical term, "hypervisible," in M. Nourbese Phillip's essay titled, "How White is Your White: On the lack of colour in the Bernardo/Homolka affair." In this essay, Philip contrasts the lack of racialization in the trial of two White serial murder suspects versus the trial of two black male suspects in a shooting at a popular middle-class restaurant in Toronto. Philip contends that black folks are often invisible to mainstream Canadian society until a crime is committed, whereupon black folks become hypervisible to racist police forces and the media. In an examination of the social construction of Whiteness, Ruth Frankenberg notes, "Racist discourse...frequently accords a hypervisibility to African Americans and a relative invisibility to Asian Americans and Native Americans" (12).

continue speaking out against the many ways that women, especially black lesbian feminists, are silenced and overlooked. Even within the feminist movement, Lorde observed, black women have had to "fight and still do, for that very visibility which also renders us most vulnerable, our blackness" (21). What confers visibility, then—whether blackness, scars, or amputated breasts—renders vulnerability. However, Lorde argued that despite the risk of vulnerability, it is better to speak out, to transform silence into language and action, since silence had never protected her and, ultimately, death would be her "final silence" (18-23). A warrior woman is also a warrior of words, one that refuses to be silent in the face of life-threatening forces. A refusal of silence involves speaking out and engaging other breast cancer survivors in dialogues about pain, suffering, and death— to fulfill what Lorde identified as the "need for every woman to live a considered life" (57-58).

By claiming the role of a warrior woman, Lorde transformed the role of women with breast cancer from that of passive victim to that of active resistance fighter who deliberates upon and furthers her survival. In the woman warrior role, women may take active responsibility for their own and others' survival, reclaim their scarred and culturally devalued bodies, and escape isolation by speaking out and engaging in dialogues with other survivors. As a warrior, the identity of the breast cancer survivor may surface rather than lie covered under make-up or beneath the false comfort of breast prostheses or breast reconstructive surgery. One of the first steps in embracing one's ill body is to "come out" with one's illness, as gays and lesbians have historically "come out" about their sexualities, and as people with non-apparent disabilities have "come out" about their disabilities and

illnesses (Hillyer, chapter 8; Wendell, Rejected chapters 1 and 2).[7] Coming out as ill

requires an embrace of one's stigmatized body and self—to take a warrior's stance, which

allowed Lorde to simultaneously identify with cancer and resist negative cultural stigmata

about illness.

As lesbians and gays—and now members of queer communities including bisexuals

and transgendered folks—know well, the act of coming out is fraught with ambivalence. It

is no easy task to claim a culturally stigmatized identity with its attendant economic,

social, and violent effects of discrimination. Tremendous work is required of those so

negatively identified to transform cultural and personal misperceptions of their embodied

lives. The power of claiming a stigmatized identity lies in the potential for self-definition

(Collins, chapter 5; Gever). Yet, what encompasses self-definition? In her article, "Male

Lesbians and the Postmodernist Body," Jacquelyn N. Zita reminds us that, despite post-

modernist aesthetics that grant discursive playfulness to identity formation and location,

people are embodied beings whose bodies are interpreted within and beyond their

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[7] Hillyer and Wendell (Rejected) claim that there are tangible benefits and costs for those who can "pass" as non-disabled; however, both argue that the benefits of coming out as disabled outweigh the costs of passing as non-disabled. Choosing to not pass as non-disabled offers one the empowering potential for self-definition and the social recognition that often determines access to medical and social resources. To identify as disabled, however, requires not only that one chooses to "come out" or identify as disabled, but also that one meets the criteria for membership (Hillyer, chapter 8). In her examination of her illness, myalgic encephalomyelitis, Wendell observes that people with disabilities sometimes do not want people with chronic illnesses to identify as disabled since they do not want the stigma of illness to attach to the already stigmatized social construction of disability (Rejected 21). Barbara Hillyer, Feminism and Disability (Norman and London: University of Oklahoma Press, 1993). Susan Wendell, The Rejected Body: Feminist Philosophical Reflections on Disability (New York and London: Routledge, 1996).

communities of belonging.[8] A large part of the power of self-definition, then, lies in the potential for dialogue and for building and expanding communities. Simply coming out is not enough.

Lorde's woman warrior space, while asserting an empowered location for identification with breast cancer, serves as an invitation not only to join in her woman warrior stance but to also share experiences of how this identification or others could help women with breast cancer live more considered lives as they fight for their common survival. She asked, "Where were the dykes who had had mastectomies? I wanted to talk to a lesbian, to sit down and start from a common language, no matter how diverse. I wanted to share dyke-insight, so to speak" (Lorde, Cancer 49). Lorde's delineation of the woman warrior identity marks off a dialogical space for like-minded women (whatever their sexualities) who, tired of being treated as victims and/or frustrated by care workers who regard their breast cancer survival as a cosmetic dilemma, wish to assemble and critically engage in their survival. The legacy of Lorde's work—especially her view of women with breast cancer as women warriors and survivors, and her insistence on the links between poverty, racism, environmental pollution and cancer—can be found in the politics of contemporary breast cancer activist movements. Her widely read book, The Cancer Journals, has served to initiate dialogue among many breast cancer survivors,

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[8] Jacquelyn N. Zita argues that male lesbians would have a difficult time identifying as such because lesbian communities would criticize their membership. The ability to identify as a male lesbian, Zita contends, depends less on one's declaration and more on one's social acceptance into that declared space. Zita does not argue for the fixity of sex, but recognizes the contingency of sex and sexualized identities. Since Zita's article, queer communities have challenged the binaries of sex, along with gender, since many of their members inhabit what could be clinically called "inter-sexed" locations, neither claiming their biological sex nor becoming "fully" transgendered (socially and physically), but preferring to remain in the transitional range, to be always in transition.

feminists and academics (see Ehrenreich, "Welcome"; Eisenstein; Frank, Wounded; Steingraber; Wendell, Rejected).

C. The Two Voices of Rosenblum and Butler: Self-Conscious Living and Ethical Wills

Despite similarities in content and structure, Sandra Butler and Barbara Rosenblum's Cancer in Two Voices surprisingly does not refer to Audre Lorde's writings about cancer. Instead, the authors draw on other feminist works on cancer: Jewish anthropologist Barbara Myerhoff's film about her search for healing and dying rituals after being diagnosed with mesothelioma, an aggressive cancer with poor prognosis (Butler and Rosenblum 64-66); and Deena Metzger's photograph of her one-breasted body with a tree of life tattooed over her surgical scar (30, 134). Other illness stories are not mentioned. However, Rosenblum and Butler do note that the rising incidence of breast cancer among women has left the members of their gay and lesbian Jewish congregation, and the wider gay and lesbian communities, struggling with two devastating epidemics: AIDS and breast cancer (54, 95-96, 181, 208).

Although Cancer in Two Voices was published after Rosenblum's death in 1988, excerpts of the book in progress were published, and Rosenblum and Butler publicly presented and read these excerpts to various audiences. From these presentations and readings, they received feedback affirming the importance of their work (Butler and Rosenblum 169, 86, 200). The strong and appreciative community feedback sustained their writing and bolstered their resolve to bear witness to cancer. Thus, prior to the actual publication of this book, their writings and talks had already touched and engaged a

number of people. Among the people directly affected by their then work-in-progress were those in their immediate circle of family and friends. Soon after her diagnosis, Rosenblum gathered friends together to tell them about her metastatic breast cancer, whose early detection and treatment were denied due to a series of medical misdiagnoses. In their sombre silence after her announcement, she realized: "I am only the first among our friends to have cancer.... Such a weighty responsibility, to be the first, yet it gave me a purpose. I am trying to live self-consciously (and perhaps die self-consciously) in an exemplary manner. Many of my friends will see their future in the way I handle mine" (12-13).

By serving as examples of two women living publicly and self-consciously in the face of illness and dying, Rosenblum and Butler created a narrative that appeals to a wide audience on numerous levels. It depicts a Jewish lesbian relationship responding to the changing demands of the crisis of a life-threatening illness. It presents narrative possibilities for experiential illness stories through collaborative writing, communion with friends, journal entries, sustained reflections, and letters. It reveals the thoughts and feelings of the primary caregiver and partner, as well as the person living with illness. It maintains, through its authors' explicitly stated intent, that people living with illness, along with their caregivers, possess a social role and responsibility to teach others about illness and suffering by learning to live self-consciously. Above all, Butler and Rosenblum's narrative offers a dialogue about experiences of breast cancer and dying between two intimates whose voices, while primarily engaging one another and their communities of family, friends, and colleagues, invite the engagement of others.

Their intent, Butler explains in the introduction, was to "write this book as a map of our experiences in the hopes that it would be of use to those of you now reading it.... We wanted to tell our story, finally, because this writing made us visible to ourselves as we were living it" (Butler and Rosenblum i). Hence, in Cancer in Two Voices, Rosenblum and Butler transformed Rosenblum's space of illness, usually a private and solitary sphere of loss and suffering, to an exemplary space for learning and teaching self-conscious living. When close friends formed a healing circle around Rosenblum after the cancer had metastasized to her lungs, Rosenblum, ever the consummate sociologist and teacher, observed: "That other people can learn from this and make their lives fuller and richer— and more real—is extremely gratifying to me" (132). Through their writing, Rosenblum and Butler, like Lorde before them, learn and teach the transformation of socio-cultural and personal values necessary to self-conscious living: to examine what is culturally negative and socially stigmatized, such as illness or dying, in order to revalue it and explore its myths, meanings, and symbolic configurations.

The conflicting struggles inherent in the transformation of values form a central narrative focus and appear starkly in two sections of the book, "Blood Money" and "The Will" (Butler and Rosenblum, 45-61 and 103-114, respectively). In these sections, Butler and Rosenblum address the circumstances surrounding Rosenblum's successful malpractice suit, which placed a monetary value—$296,000 plus $25,000 annually—on her life, leaving her with more money than she had ever imagined (57). Rosenblum and Butler regard this money as "blood money," something that takes the place of the quality and quantity of life Rosenblum could have had (59, 104-105, 108, 112). "A price tag on Barbara's life," Butler sadly ruminates, in exchange for the series of misdiagnoses by

physicians and technicians at a public hospital that resulted in Rosenblum's cancerous

tumour being overlooked (57). Unlike Rosenblum, Butler always had a private physician,

whose attention was more meticulous and generous than that of Rosenblum's rushed

doctors at the public clinics and hospitals. Only when her medically disregarded symptoms

worsened did Rosenblum seek out and interview private physicians for her care. Butler's

middle-class upbringing and Rosenblum's working-class childhood resulted in their

different expectations of health care (23-27). In a two-tiered health care system where

publicly funded health services often offer compromised care, their different class-based

expectations translated into a shortened life for Rosenblum. Thus, the blood money not

only symbolized a sorry exchange for Rosenblum's life, but it also represented gaps in the

health care expectations of, and delivery of service to, economically impoverished versus

economically affluent people. These gaps are as enormous as that between life and death.

Rosenblum and Butler's ambivalence towards the blood money culminated in their

realization that the money would outlast Rosenblum's life—Rosenblum would have to

decide what would become of the money after her death. In their deliberations, both

struggled to examine the meaning and role that money had played in their lives. For

Butler, money translated into love and care; the one for whom one cares deeply would be

left the most money (Butler and Rosenblum 109). When Butler realized that she would

have no say in the distribution of the malpractice money, that it was Rosenblum's money

and she would not receive the bulk of it, she was confused and uncertain about her

importance in Rosenblum's life. Yet, she realized that money was not the reason they

became life partners and chastised herself for "constructing an equation that makes money

equivalent to caring" (110). For Rosenblum, her life had never been about trying to

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accumulate money but about finding time to read and think (59). That the time she wanted

was replaced by money is a cruel irony. On many occasions, Rosenblum expressed her

hatred of the money, for it represented the life she would not have and the life she did

have—a life of doctor's appointments, chemotherapy, fatigue, vomiting, and baldness

(104-105). She did not want people to enjoy her money, for the money came at the price

of her life—a calculated cost of her suffering—and thus she wrote with angry resentment:

> I don't want to leave anyone anything.... I am ashamed of these feelings, of
> not wanting to leave any money to my important people. I don't want
> anyone to have a good time with my money. I'd sooner give it away to
> groups and organizations whose work I support, who do good things in the
> world. This blood money is in need of redemption and good works is the
> only way I can imagine redeeming. (108)

In the act of drawing up Rosenblum's last will and testament, then, Rosenblum and Butler

had to reconsider and re-evaluate the socially corrupted value of money. Butler

summarized the task well when she observed that what Rosenblum had to do was translate

her values and principles into ratios in order to apportion her money, and that, ultimately,

"her will translates the language of the heart into that of a bloodless, legalistic document"

(107, 110). Rosenblum endeavoured to redeem the corrupted value of her money by

allocating it to organizations that work towards social and political change, and to her

loved ones with specific purposes in mind, namely that the money enrich their lives with

learning—something that Rosenblum valued immensely for herself and for others. Hers,

she resolved, would be a legacy of learning.

Contemplations of the legal will, alongside other reflections on living with breast

cancer, enabled Rosenblum to clarify her personal aesthetics, social values, and political

principles, and, in the process, narrow down issues and ideas that held significance in her

life (Butler and Rosenblum 69, 127, 59). She communicates her newfound clarity in letters to friends and family, especially in letters intended for her young nephew, Asher. In addition to leaving money for Asher's education, she began, as her condition worsened, to write him a series of thirteen letters, of which one is to be given to him at each birthday and then all are to be bound in a book for his *bar mitzvah*. "Each essay," Butler relayed, "examines a dimension of living ethically and morally.... She writes of courage, honor, passion, love. They are inscribed to Asher, but are also for Ruth [(Rosenblum's sister and Asher's mother)] and for me. Part of her legacy to us" (191). These letters, explained Rabbi Kahn, whom Rosenblum consulted in the last months of her life, follow the tradition of ethical wills, which dates back to the Middle Ages (192). Rosenblum read one of her letters to Asher to her assembled friends a month before her death, explaining that she wished him a "feeling of fullness"—what she believed was "essential for a good life" (186).[9] Fullness represents not only the opposite of emptiness and loneliness, but also an

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[9] With her letters to Asher and her writings in Cancer in Two Voices, Barbara Rosenblum has bequeathed to us ethical wills that examine an issue central to the analyses of many great historical thinkers, including Aristotle, and their followers: the necessary conditions for a good life. While many may write about the necessities for a good life, Rosenblum's words are particularly poignant, because she is living with a terminal illness and her search for what constitutes a good life seems a race against time. In his literary examination of AIDS diaries, Facing It: AIDS diaries and the death of the author, Ross Chambers argues that the discursive authority of these diaries appears to arise from the author's death—a "post-mortem authority," as if a voice from the grave, or as if in a last will and testament (95-96). Discursive survival, premised on publication, occurs through the act of writing where "the telling of the story *survives* the story that is told" (4; original emphasis). With an authority "borrowed" from death, AIDS diaries—many of which were written in the late 1980s and early 1990s—that adhered to the gay and lesbian politics of visibility (e.g. Queer Nation's organized "kiss-ins" where people chanted, "We're here, we're queer!") could extend that visibility to "audibility" by privileging eyewitness accounts of AIDS and homophobic discrimination and violence (20-21). While Chambers does not examine why an author's proximity to death or physical vulnerability confers an authority on life, he does ascertain the effects of such authority on their authors and readers. For authors, their narrative authority transmits or relays a responsibility for witnesses to continue witnessing (7-8). For readers, the author's death instills in readers an awareness of the responsibilities of "readerly survivorhood" (22). Rosenblum's writing also assumes an

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"enlargement of...feeling and perception" and a fine discernment of human experiences, such as pain and its various manifestations as grief, sorrow, and disappointment (186-87). The ability to distinguish human experiences precisely, Rosenblum proposed, allows one to be more alive. Within the letters to Asher, Rosenblum's legacy of learning finds a more richly detailed and immaterial form than that of her last will and testament.

Rosenblum offers material (money) and immaterial (reflective writing) aspects of herself with the two types of wills. Whereas the legal will stipulates the division of material possessions upon her death, the ethical will bequeaths knowledge as formed and constructed by her experiences before and with breast cancer, and by her reflections on social values and political principles. Instead of a material summary of a life, one is left with an acute witnessing of a life—an experiential inheritance. In this respect, the body of Rosenblum's ethical will is not limited to the letters to Asher, but encompasses the entirety of the book. Cancer in Two Voices, with its explicit intent to show how to live self-consciously—in moral and ethical magnitude, in the face of illness and death—constitutes an ethical will. In their writings, Rosenblum and Butler attempt to convert the experiential intricacies of pain and suffering into an appreciation and discernment of life's values (see also Ehrenreich, "Buddy").[10] "There are a lot of lessons that come with this disease, or

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authoritative tone—an authority borrowed from a shortened life, and also from illness, injustice and suffering. Her narrative account of attempting to live a considered life challenges readers to consider their own "readerly survivorhood."

[10] Barbara Ehrenreich observes that many mainstream breast cancer narratives espouse the "redemptive powers of the disease," presenting breast cancer as offering "opportunities for self-improvement" (Welcome 49; see also Biehn). For example, some breast cancer survivors maintain that cancer has been a blessing in disguise—more specifically, that the threat of dying earlier than anticipated has triggered a welcome revaluation of their values and goals. Ehrenreich criticizes the "general chorus of sentimentality

maybe it's just that you learn to make them into lessons," muses Rosenblum (Butler and Rosenblum 193). As with all experiences, illness—specifically, breast cancer—is what you make it. Knowledge or revelation does not magically accompany experience—illness or otherwise. Rosenblum and Butler's individual and united attempts to make sense and use of Rosenblum's breast cancer lay the dialogical and ethical foundation of the book: living ethically and morally involves dynamic and interactive processes. Their lessons become our lessons.

The concept of ethical wills expands our understanding of the potential value and role of illness narratives. When an illness narrative, such as Cancer in Two Voices, assumes the form of an ethical will, it can serve as a vehicle for ethical engagement through its translation of illness and suffering into proffered tenets of living and dying well. As an ethical will, Rosenblum and Butler's illness narrative reveals the challenges of

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and good cheer" (48) around breast cancer, as evidenced by glitzy fundraisers that celebrate fashion and cosmetics, or the selling of stuffed animals and cute necklaces that infantilize women with breast cancer (46). Despite popular cultural myths that promote positive thinking as conducive to healing, Ehrenreich warns that this "relentless brightsiding" may downplay the very real threat of cancer to a woman's life (49). Unlike other women with breast cancer, Ehrenreich steadfastly resists such "brightsiding" and pointedly asks, "Why give a malevolent disease credit for the adjustments we make in order to survive?" (Buddy 255). In her opposition to the cheerfulness of mainstream narratives, Rosenblum also frankly expresses her anger and resentment. She repeatedly writes that she hates those who misdiagnosed her cancer and hates her cancer and its effects on her life and goals (Butler and Rosenblum 26, 82, 104-105, and 150; see also the article on Dr. Jerri Nielsen, "My Cancer Battle at the South Pole," by Joanna Coles). Herein lies the contradiction within illness narratives: how does something positive come out of something negative (illness and suffering), without platitudes and false cheerfulness? Unlike other stigmatized monikers, such as race, gender or queerness, illnesses and their painful and uncomfortable effects cannot be easily transformed into emblems of pride since they are inherently unpleasant. Whereas one can take a devalued quality or act, such as black skin or queer sex, and promote it as beautiful, desirable, or revolutionary, it is generally agreed that illness, suffering, and pain are not enviable experiences or conditions. Disability activists and scholars have examined this dilemma in their struggles for a disability pride movement (Crow; Hillyer; Wendell, Rejected). Often, these writers conclude that the effects of disability and/or illness, such as physical discomfort and suffering, can serve as enlightening life lessons about social and personal vulnerabilities, and emphasize the need for increased social accountability to, and responsibility for, vulnerable persons.

utilizing one's experience of illness to benefit others. Because illness is culturally

stigmatized and its effects can be physically and psychologically debilitating, it is no simple

matter to revalue illness experiences. Illness narrators may draw on the biblical idea that

trials and tribulations, and all manner of suffering, can serve as lessons in faith. What

makes Butler and Rosenblum's narrative unique is their mutual engagement with each

other and with illness in order to forge experiential routes for family and friends to

maintain their faith (religious or otherwise), political convictions, and ethical principles.

Their critical stance against the all-too-common social and cultural laxity towards breast

cancer prevention and detection, and women's health in general, especially within public

clinics and hospitals, calls for improved medical accountability and responsibility. As

feminists, Jewish lesbians, and members of gay and lesbian communities, they recognize

the need for solidarity against what they call the epidemics of breast cancer and AIDS

(Butler and Rosenblum 54). Their narrative, like Lorde's, is a political call-to-arms for

women's health. Instead of being women warriors, however, Rosenblum and Butler

propose an expansion of the identity and role for women living with breast cancer: life's

teachers and role models.

For many academics, like Rosenblum and Myerhoff, their illness narratives,

especially if they become their final bodies of work, may resemble a final theoretical

argument or thesis position (for Lorde, it was a collection of poetry).[11] In his literary

analysis of AIDS diaries, Ross Chambers likens anthropologist Eric Michaels's diary to

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[11] In the posthumously published collection of poetry, The Marvelous Arithmetics of Distance, Audre
Lorde explored her experiences of living with advanced cancer alongside her thoughts of dying.

that of an academic position paper. Like an academic presenting a position paper wherein one must defend one's views, Michaels inhabits a threatened position as a gay man living with AIDS in a homophobic society in rural Australia (Chambers 95-96). From this location, he must defend his life from the AIDS virus and from homophobic people and policies within various social systems and in daily interactions. For this reason, Chambers suggests that Michaels's diary cannot simply be a testimonial but must, in order to address the hostile discrimination of a homophobic health care and social system, assume the shape of a "difficult patient's manifesto" (99). Because the diary will survive the author's death, Chambers argues, one of its social functions is to rouse readers' concerns about Michaels's experiences of injustice during illness and dying (101). Thus, the diary must function as a counter-attack against discriminatory fears that would deny competent care for people, especially gay men, living with AIDS. As a difficult patient's manifesto, AIDS diaries (and, I would argue, illness narratives in general) may disrupt the readers' complacency by making them uneasy and anxious about the counter-attack they are witnessing (111-13). Chambers theorizes that this "anxious reading" promotes engagement—that such a militant tone disturbs readers and, ideally, incites them into concerned action.

To supplement or precede (for those living with non-terminal illnesses) the last will and testament, illness narratives can take the form of ethical wills, position papers, or manifestos that detail one's argument with society's devaluation and discrimination against people living with illnesses—especially chronic and terminal illnesses such as breast cancer

and AIDS, whose populations inhabit culturally and, often, economically[12] disenfranchised positions, and whose lives depend on prolonged contact with multiple facets of the often overburdened, impersonal and discriminately fallible health care system. As social documents, illness narratives can supersede the power of the last will and testament by instigating readers into action through documented and witnessed incidents of injustice. Both Lorde's and Rosenblum and Butler's narratives have united women living with and without breast cancer in dialogues about breast cancer prevention, detection, and treatment. Their words, ideas, and strategies resonate to this day within communities of breast cancer survivors.[13] As ethical wills, position papers, and manifestos, then, illness narratives aim to engage readers to respond to social dialogues about ethics and justice by emphasizing the dynamic and social processes of teaching and learning with and among vulnerable and ailing bodies.

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[12] Anne Hunsaker Hawkins observed "that in none of the pathographies I have discussed is the cost of the treatments the patients undergo so much as mentioned; few discuss limitations of insurance coverage or problems in obtaining medical care—even pathographies about AIDS. This suggests that books of this kind are written by the middle class or the affluent...[and] their authors seem educated and articulate" (159). Also, the physical demands and financial costs of living with chronic and terminal illnesses can further and differentially weaken and impoverish people from different income and class levels, and gender and racialized identities (Sherwin, chapter 11). Hawkins borrows the term "pathography" from Sigmund Freud and Oliver Sacks to denote a combination of biography that is influenced by pathological elements (178; will be discussed in chapter 3).

[13] Unfortunately, corporations that focus only on cures and not preventative measures have appropriated and often dominate the current discourse around breast cancer (Ehrenreich, Welcome; Eisenstein).

In The Wounded Storyteller and, to a lesser extent and with a more preliminary analysis, in At the Will of the Body, Arthur Frank contends that people living with illness and disability possess a social responsibility to tell others about their experiences, while everyone else has a responsibility to listen. Such telling and listening constitute a giving and receiving of witness—an embodied endeavour that promotes a form of communion, since "[i]llness stories require an interplay of mutual presences: the listener must be present as a potentially suffering body to receive the testimony that *is* the suffering body of the teller" (Frank, Wounded). The mutuality of sufferer/teller (narrator) and receiver/listener (reader) within the testimonial relationship exists because, as sufferers need to share their suffering, listeners also need to be needed (to be discussed later). To bear witness to, and to receive witness of, suffering—that is, to share suffering— constitutes a concerned engagement, an exchange of needs that bespeaks mutual care.

Just as Chambers contends that AIDS diaries—through their manifesto-style belligerence and posthumous influence—can instigate an "anxious reading" that elicits concern and analysis, Frank asserts that experiential illness stories in general, with their accounts of embodied pain and suffering, set the stage for relationships of mutual need and concern. The elucidation of experiences of bodily ailments and suffering within illness stories, whether through the act of writing or reading, arouses feelings of empathy and care. By framing the acts of telling and listening to experiences of illness and suffering as co-extensive social responsibilities, Frank claims an ethical dimension to illness stories. Through illness stories, we become accountable for our own and others' experiences of

suffering because "the witness makes a witness of others.... When someone receives the testimony of another, that person becomes a witness, and so on" (Frank, Wounded 142). Through this shared and transmitted responsibility, we enter into relationships of care.

Caring for ill persons involves listening and responding attentively to the particularities of their experiences; ultimately, caring for an ill person necessitates an understanding of her or him (Frank, At the Will 48-49). From his own experiences of illness, Frank asserts that "[h]uman suffering becomes bearable when we share it. When we know that someone recognizes our pain, we can let go of it. The power of recognition to reduce suffering cannot be explained, but it seems fundamental to our humanity" (104). If the act of listening to suffering ameliorates that suffering, then listening is a moral act and is itself an ethical enterprise. For this reason, he believes that "[s]imply recognizing suffering for what it is, regardless of whether it can be treated, is care" (101). This "power of recognition" is the defining component of ethical listening and resembles the fine discernment of human experiences—particularly, pain—that Barbara Rosenblum discussed in a letter to her nephew, wherein she extolls the importance of distinguishing different kinds of pain such as grief and sorrow (Butler and Rosenblum 186-87; see previous discussion in section C). When we are able to discern the many facets of pain, Rosenblum maintained, we learn to feel more fully and, as a result of this enlarged feeling, to live more fully. Within illness narratives, then, one's ability to recognize pain and suffering, and to continue to witness pain and suffering, can be both the process and intended goal of testimony. Through illness narratives, we learn to recognize suffering, and in that recognition, we come to care for one another. Illness narratives—in the form of ethical wills, manifestos, or testimonials—lay the groundwork for relationships of mutual caring.

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They are documents, written with care, which bid us to live self-consciously enough to care.

In addition to caring acts of listening and responding to people living with illness, we must also enable their experiential telling and protect the spaces in which they are able to tell. By emphasizing the value of illness narratives—whether individually as documents, or collectively as a genre—we assert the experiential value of people living with illness, and thus resist their relegation (or, in some cases, further relegation) to the margins of society.[14] We may see similarities between different illness experiences, and come to care for ill persons as individuals and as parts of a larger social whole whose experiences have been historically denied. To care for a sick person, we must see her or him as a personal and social witness. Frank argues for the social importance of the embodied witnessing of ill people through two main ideas: the *pedagogy of suffering*, which posits that people living with illness and disability can teach us valuable lessons about physical and psychological vulnerability and suffering (Wounded 145-54); and *dialogical engagement* between writers and readers, which explores how the destabilized consciousness of the narrative voice invites readers into dialogical processes ("Illness").

The pedagogy of suffering—or simply put, what we can teach and learn about suffering—counters the dominant cultural misperception that ill persons have nothing to

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[14] Even prior to illness and disability, many folks already inhabit marginalized locations. Illness may compound their sense of marginalization, and their marginalization may compound their illness (Sherwin chapter 11). For economically disenfranchised folks, their inability to access adequate and healthy foods or their exposure to toxic environments may prolong or worsen their illnesses. In addition, malnutrition may be a contributing factor in their illnesses. See Susan Sherwin, No Longer Patient: Feminist Ethics and Health Care (Philadelphia: Temple University Press, 1992).

offer.[15] To examine what ill persons can offer and teach us requires, foremost, the removal

of conceptual blocks supported by structural discrimination. Ill persons seem unable to

offer much to loved ones or to society because, as the social constructionist theory of

disability (and chronic illness, since there is considerable overlap) claims, disabling social

structures and cultural views often misrepresent them as emotionally and physically needy,

as perpetual "takers" and not "givers." As a result, ill persons find themselves excluded

from social participation and rendered incapable of fulfilling social obligations, because

they inhabit marginalized locations in ableist environments that lack accessible services and

structures. What ill persons can offer, then, is limited by what society will not offer or

grant them.

Since social and ethical theories usually frame social relationships in terms of what

we owe each other—especially what is owed economically and socially to marginalized

persons—we are morally and socially obligated (e.g. formally through taxes, or informally

through women's socialization to do unpaid care work) to take care of those who are

unable to care for themselves. However, structural and organizational discrimination

against physical and psychological vulnerability and incapacity makes the justifiable

demands of ill and disabled persons seem excessive. In other words, we owe one another

support, but surely not *that* much. The word *that* conveys the limits of what we deem is

reasonably owed to people with illness and disability in a world of limited social resources,

including health resources. Herein lies a crucial question: is the lesson of suffering worth

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[15] While Frank focuses primarily on the contribution of illness to the pedagogy of suffering, he does acknowledge that illness is but one out of many conditions that teach us about suffering (Wounded 154).

learning? If suffering persons require a significant portion of our social resources and personal energy, is the give (lesson) equal to the take (resources of caregiving)?

In his formulation of the pedagogy of suffering, Frank looks to Nancy Mairs to challenge the "*that* much" of the "how much" we deem justly appropriate in the allocation of social resources for people living with illness and disability.[16] Are there mitigating factors, such as cultural discrimination, that limit what we deem valuable about ill and disabled persons, and thus what is owed them to ensure their opportunities to teach us? According to Mairs, the relationship between the sufferer/teller and the listener may be easily misconstrued and maligned due to our cultural misperceptions of need and obligation as propagated and reinforced by the social organization of charity. Charitable organizations have assumed dominating roles over people with disabilities (and other disenfranchised folks), because relationships of mutuality have been corrupted. Mairs believes that people possess abundances and lacks, and that relationships between people embody an exchange of these abundances and lacks (Frank, Wounded 148-49). Charities serve not only those in need, but also those who wish to be needed. Giving to charities allows donors to feel needed, which is a tangible benefit, for it affirms their social importance and sense of shared humanity. Also, donors, especially wealthy or corporate ones, benefit economically from charitable tax breaks. However, the concept of charity masks the fulfillment of the donor's need to be needed by disguising it as selfless virtue. In Mairs's words, "the 'nice' need the needy to be other to their niceness, but...the nice

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[16] See the book, Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy, by Anita Silvers, Mary Mahowald, and David Wasserman for a cogent discussion of distributive justice and resource allocation for people living with disability.

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cannot acknowledge their need for the needy" (Mairs in Frank, Wounded 148-49). Thus,

while a co-dependent relationship exists between donors and recipients, it is continually

denied. As a result, what should be a mutual relationship twists into a grotesque form of

domination, wherein those in need are considered dependent[17] upon those who give

because their need eclipses any potential personal and social contributions they may

make.[18]

The experience of living with multiple sclerosis informs Mairs's argument against

the misrepresentation of people with disabilities and illnesses as burdens to families and

society. Many women with disabilities and illnesses are themselves caregivers: in the

caregiving roles of spouse, mother, daughter, friend, and/or professional caregivers if they

are able to retain paid work (Dyck, "Hidden"; Mairs; Wendell, Rejected). Notwithstanding

the reality that the physical work of caring for people (often the work of women,

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[17] Some social activists argue that charities, like food banks, are simply "band-aid" solutions that may reinforce dependence upon the social system. Charities imagine recipients as passive and helpless. Similar to Anita Silvers's concern that the replacement of an ethics of equality with an ethics of caring may exacerbate paternalistic power dynamics in that caregivers can choose to care or not, while recipients of care cannot choose from whom they will receive care (Silvers in Wendell, Rejected 143-44), charitable donors can always choose where to donate their money, while recipients cannot reject their sources of funding. Within the feminist, and gay and lesbian communities, corporate funding of grass-roots organizations has posed a similar dilemma. The organizers of the Toronto AIDS walk could not afford to reject sponsorship from drug companies that once denied AIDS patients drug access. Charities, while beneficial to many, can undermine social justice—by giving people the option to help or not, they facilitate the transition of what could be construed as social obligations into supererogatory acts of virtue.

[18] The relationship between people living with illness and/or disability and their caregivers is another case in point. Often, the relationship is presented as asymmetrical; care is seen to flow in only one direction: from the person giving care (caregiver) to the person receiving care (care-taker). In The Rejected Body, Susan Wendell offers an insightful account of the ramifications of such an asymmetrical view on our perceptions of people living with disability and/or illness as personal and social burdens (chapter 6). While Wendell does not discount the important and hard work of caregiving—performed disproportionately by women, especially women of colour—she advises us to consider the care and affection that people living with illness and/or disability can and do give back to their caregivers. Such a consideration, she argues, is vital to a feminist analysis of an ethics of care.

especially women of colour) is often asymmetrical, the act of expressing care (including affection, love, empathy) can be symmetrical (Frank, <u>Wounded</u> 150). Moreover, people living with illness and disability do perform care work for others who may be ill, disabled, non-ill, or non-disabled. Thus, we need to appreciate the ways in which people living with illness and disability can and do fulfill the needs of others—by affirming their sense of humanity, by doing caregiving work for them, and by caring for them. Rather than an ethic of responsibility, Mairs calls for an ethic of *extensive* responsibility, whereupon we frame our relations in a more reciprocal manner (Mairs in Frank, <u>Wounded</u> 148-49). Our responsibility to one another should not be viewed as unilateral burdens, but as a means of fulfilling our needs. We benefit from being mutually responsible to one another, since our responsibility to others implies that others are, in turn, responsible to us, and our sense of responsibility allows us to feel needed, which affirms and strengthens within us a positive sense of self.

Beyond teaching us a discernment of the experiences of illness and suffering, how exactly may illness narratives affect the lives of those living with and without illness and disability? From a medical ethics perspective, Rita Charon contends that narrative studies help improve the relationship between professional caregiver and patients by enabling caregivers to: (a) "recognize the narrative coherence...of the patient's life"; (b) recognize "multiple tellers of the patient's story," and distinguish different audiences and interpretive communities; (c) "examine contradictions among the story's multiple representations"; and (d) help patients and other involved persons in ethical decision-making (Charon in Frank, <u>Wounded</u> 155). Charon's proposed benefits extend beyond the realm of medical ethics since they can be applied to any situation where people must respond to, and interact with,

people living with illness and disability. Frank describes Charon's narrative ethics as a kind of "narrative sensitization" (155). We learn by becoming sensitized to the experiential content and narrative form.[19] Yet, not all instances of an embodied witnessing of illness lend themselves to narration. Will we be affected by stories that are not told well?

For Frank, narrative and thus pedagogical limits reside in the body of the ill person. Certain bodies, he argues, are more oriented towards testimony than others; he calls these "communicative bodies" (Wounded 40, 48, 52, 163-65). His description of a "communicative body," which he admits is an ideal and idealized type (48), resembles Audre Lorde's "considered life" (Cancer 57-58) and Barbara Rosenblum's "self-conscious living" (12-13).[20] However, Frank explicitly states that his description of an ideal and

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[19] In her book Love's Knowledge, philosopher Martha Nussbaum asserts that literary fiction, through its cultivation of a "perceptive equilibrium"—a fine discernment of the complexities within human relationships and motivations—can serve as an ethical training ground. Literature can teach us to be better persons. Nussbaum's critics question the practical translation of her theory. How do we evaluate which pieces of literature are worthy of being ethical training grounds? Does the act of reading good literature necessarily motivate one to live a good life? While there are limits to Nussbaum's argument, many of which she admits and acknowledges, her idea that literature can teach us moral lessons by familiarizing us with details of human strengths and weaknesses resounds within Arthur Frank's explication that people living with illness inhabit an important social role as experiential narrators. Although Nussbaum's work focuses on famous fictional works in the Western literary canon, while Frank's work evaluates a specific form of autobiographical non-fiction, they both examine narrative ethics—the ways in which the writing/writer affects the reader/listener, and, in Frank's case, how the act of writing/telling affects the writer/teller. Both express the possible cultivation of relationships beyond the text: what we read can influence how we understand ourselves and relate to one another.

[20] Frank suggests four ideal body types (disciplined, mirroring, dominating and communicative) that reflect different approaches to what he calls the "body's problem with illness," which involves issues of control, desire, other-relatedness (i.e. how we relate to other embodied lives) and body-relatedness (i.e. how we relate to our own embodiment) (Wounded chapter 2). Frank writes, "My thesis is that different bodies have 'elective affinities' to different illness narratives. These elective affinities are not deterministic. Bodies are realized—not just represented but created—in the stories they tell" (52). These different body types, he explains, are not "mutually exclusive or exhaustive" (51). At different times, in

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idealized communicative body, with its affinity to particular narrative forms, is not intended to encourage a dismissal of other body types and their narrative forms. Rather, he argues that its idealized presence permits a distinguishing of various body types and an elucidation of their locations with respect to the ideal. Frank intends his typology to promote a prescriptive norm against which an ethics of the body may be oriented. Just as Lorde's appeal for a "considered life" and Rosenblum's proposal for "self-conscious living" allow for an interpretive range against which a life may be deemed "considered" or "self-conscious," Frank posits the "communicative body" as a measure for reflexive monitoring (Wounded 51). "Becoming a communicative body is an ethical end, a telos, for a life to aspire to," Frank notes, and "[b]ecause this telos is never fully achieved...the communicative body is not a fixed state but a *recursive process*" (163-164). In other words, the ill body is realized through its embodied telling or witnessing (165). In working towards becoming a communicative body, in attempting to live a considered life, and in struggling to live self-consciously, ill narrators discover their bodies as they give witness to them. The narrator's self-actualization contributes to the mutuality of the witnessing moment: the distinction between teaching and learning dissolves. In addition to allowing ill sufferers to share and thus lessen their suffering, the writing of experiential illness

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different locations, an ill person may assume a combination of body types to varying degrees. For Frank, the ideal and idealized body type for narration is the communicative body (48). While Frank describes different body types and their "elective affinities" to certain narrative forms, he does not discuss their potentially differential reception by witnesses and readers. In chapter four, I will explore the responsibilities of witnesses to these different body types and narratives—specifically that, as witnesses, we should not blame the lack of "communicative bodies" for our inability to listen to ill persons' stories.

narratives allows them to realize their bodies in illness. The act of writing necessitates an

organization of embodied experiences into a coherent story and self.[21]

According to Frank, ethical dilemmas and their lessons within and through illness

narratives substantiate the importance of the pedagogy of suffering, enabling us to argue

for the social value of giving and receiving witness to illness and thus for the social value

of the experiences of people living with illnesses and their caregivers. It seems as though

the pedagogy of suffering primarily addresses non-disabled and non-ill persons and

challenges the cultural devaluation of, and social discrimination against, people with

illnesses and disabilities. An outline of what experiences of suffering and pain during

illness may teach us—that is, the establishment of a pedagogy of suffering—compels us to

reevaluate a contributing factor to the stigmatization of illness, namely, the fear of

suffering and pain. The pedagogy of suffering counters the dominant discourse of health

and its myth of the strong, invulnerable, and pain-free body by exposing the suffering body

to the "potentially suffering body" (Frank, Wounded 144). Ideally, this communion will

ameliorate the sufferer's pain, and dispel the potentially suffering body's fears. However,

despite the pedagogy of suffering, the act of sharing suffering may still exacerbate fears

and thus compound suffering. Lessons cannot be forced. But illness narratives, as

pedagogical tools that teach suffering, can at least provide textual locations for learning.

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[21] See Anne Hunsaker Hawkins's discussion that illness narration parallels the psychological process of "psychic rebuilding" in a person's "counterimpulse" to recover and make sense of painful, traumatic, and disorienting experiences (24). Hawkins cites Robert Lifton's 1967 study on survivors of Hiroshima, which proposes that, in order to deal with trauma, one works through an imaginative and interpretive process—which Lifton calls "formulation"—necessary for re-establishing a sense of personal order, self-integrity, and social connection (Lifton in Hawkins 23-24). Building upon Lifton's idea, Hawkins suggests that illness narration may "be seen as a final stage in the process of formulation, completing the bridge between the suffering self and the outside world by an overt act of communication" (25).

Yet, what may an ill person learn from illness narratives, from the pedagogy of suffering, if her or his body is itself a testament to suffering? Of what relevance are illness narratives to ill persons and their caregivers?

In The Wounded Storyteller, Frank imagines the suffering body of an ill person communing with a *potentially* suffering body in a relationship of embodied witnessing. In his paper, "Illness and Autobiographical Work," Frank considers the communion between two suffering bodies: ill embodied witness and ill recipient of witness. In other words, what can illness narratives and the pedagogy of suffering teach or offer a fellow sufferer? To consider this question, Frank examines two qualities of experiential illness narratives: the potentially dialogical engagement of narration and the presence of a destabilized narrative consciousness. Frank suggests that autobiographical work, including illness narratives, requires the participation of the reader/listener and is "not a spectator study but a relation" ("Illness" 22). The quality that would permit reader/listener participation involves the idea of a dialogic or polyphonic narrative form (7), which Frank borrows from the literary critic Mikhail Bakhtin (1895-1975).[22] According to Bakhtin, a dialogic or polyphonic narrative consists of competing narrative voices. This contrasts with the single authorial voice of the more common monologic narratives. Polyphony, Frank claims, invites readers/listeners to co-tell the story, and, in the process, makes them the dialogical other in the telling of the author's story (21). Polyphony or dialogical processes within narratives is achieved through the presence of a destabilized narrative consciousness, and

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[22] J.A. Cuddon, The Penguin Dictionary of Literary Terms and Literary Theory, 3rd ed. (London: Penguin Books, 1991).

such destabilization arises from a narrator's sense of surprise, or discovery of an existential "brokenness" (8-10, 30-32). A destabilized narrative consciousness creates a narrative rift, an opening through which other voices, including the reader's, may enter into the story. Dialogical processes within narratives create the condition for what Frank earlier described as the communion of embodied witnessing. "The premise of the dialogical perspective," Frank explains, "is that existential wholeness is inherently constituted in relationships with others" (31). Thus, dialogical processes may remedy the feelings of existential brokenness that illness occasions in the writer and reader, and can extend into possibilities of identity formation, since we refine our understanding of who we are through relationships with others (7, 31-32). If writers realize their ill bodies in narration, and if dialogical processes involve readers in that narration, then the readers' bodies are also realized through such narration. Hence, for people living with illness, the reading of illness narratives may serve as a process for self-realization and identity formation, and, potentially, community-building.

The examination of dialogical processes brings to light a unique quality of illness narratives: the destabilized narrative consciousness may be a condition of the narrator's illness. Many illness stories are written with the help of intimate witnesses—people close to the author—or completed by intimate witnesses should the author's death precede the narrative's publication. In Slow Dance: A Story of Stroke, Love and Disability, Bonnie Sherr Klein could not recall what had happened to her at certain points during her hospital stay because of the effects of her stroke. To fill in the mnemonic gaps, she called upon the memories of others to reconstruct what had happened. Although Sandra Butler was the one responsible for organizing the narrative for publication after Barbara Rosenblum's

death, Rosenblum and Butler jointly wrote <u>Cancer in Two Voices</u>. Their book is overtly

and intentionally polyphonic and is a good example of dialogical processes: they directly

address each other and their family and friends. The ill narrator's destabilized

consciousness may also be a co-created product of the reader's anticipation of the

author's death or physical relapse. In any event, the possibility that illness narratives may

be more conducive or vulnerable to dialogical processes than other narratives (with the

exception of disability narratives) has important implications for the genre of illness

narratives.

First, the perceived destabilization of the narrative consciousness—or,

compromised narrative authority—mirrors the vulnerability of the ill narrator and,

consequently, promotes dialogical engagement of readers. Second, the ill narrator's

authorial vulnerability necessitates other voices to tell the tale, as in the case of Klein's

reformulation of her hospital experience. Finally, dialogical processes within illness

narratives allow a free flow of what Frank describes as outward concentric circles of

witnessing: the ill narrator, as the primary witness, inhabits the center, and then makes a

witness of others (<u>Wounded</u> 142). Citing texts by children of Jewish Holocaust survivors,

Frank visualizes expanding "levels" (primary to secondary to tertiary, and so on) of

witnesses and their continuing responsibility to bear witness (142-43). Here, the voices of

intimate witnesses come to the fore. Experiential illness narratives are often written solely

by, or with the involvement of, intimates (Hawkins). Many persons whose bodies bear

witness to illnesses do not or cannot narrate their own stories. Due to financial, cultural,

or personal constraints, due to the hard work of surviving illness and suffering, many

people living with illness do not possess the energy or resources to write their stories.

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However, for many intimates, myself included, writing about the suffering bodies we witnessed at the secondary level allows us to engage in a dialogue with the primary witnesses of suffering, to create our communion with them, and to open into a space of communion with others.

For people living with illness, their caregivers, and their intimate witnesses, illness narratives, with their quality of dialogical engagement, may offer an avenue for self-realization and identity formation that, in turn, may initiate further dialogues that result in the creation of other illness narratives. In reading illness narratives, ill persons may realize their own ill bodies and embodied witnessing. Caregivers and intimate witnesses may learn, through dialogical engagement and communion with the ill sufferer, to realize their own bodies and their implicated commitment to continue witnessing. And that continued witnessing may assume the shape of an illness narrative. Witnessing begets witnessing; illness narratives beget illness narratives. My narrative about my mother's experiences of breast cancer will employ ideas gleaned from the illness narratives examined within this chapter. My narrative will be constructed as a dialogical engagement with these narratives: to commune with these ill narrators in order to create a space of communion for the memory of my mother.

Chapter III

The Mother Who Was Ill: Race, Class, and Citizenship

When my mother was diagnosed with breast cancer in 1996, she asked me how

cancer spread. In my clumsy mixture of limited Cantonese and English, I responded that if

the cancer cells go into the lymph glands under the armpits, then it might spread through

the bloodstream. She turned to me and asked, "What is a cell?" A cell is the building block

of life. Life and cancer begin with a cell. A cell is the foundational unit of the scientific

paradigm that defines life—a paradigm that came to define and alienate my mother's life.

She navigated the Western scientific and English languages that appeared increasingly

foreign to her tongue. Medical procedures and words, such as mastectomy, cancer, and

white blood cells, renamed her life and body in unfamiliar terms. As her linguistic and

scientific translator, I told her culturally appropriate medical stories about her cancer—

stories I had heard and been taught. Stories about the immune system allowed many

around my mother, including myself, to narrate her body back to her (Martin).

Witness to my mother's illness with breast, then lung, cancer, I am situated as the

currently non-ill, non-disabled, health-care-trained daughter who interpreted and explained

diagnoses and treatment options. I am privy to resources of energy and time, along with

educational training and opportunities beyond and within feminist academic spaces, which

permit a different kind of embodied witnessing than that of ill persons described by Arthur

Frank (Wounded). As a first-generation,[23] Canadian-educated immigrant who labours as a

health care worker and continues to study at university, I inhabit a particular place in the

health care and education systems.

Unlike her health care workers and the hospital staff, I am bound to my mother's

embodied narrative—I cannot leave it and go. As a dutiful daughter, I am bound by family

dynamics and responsibilities. "Much of what happens at any given moment in families,"

Hilde Lindemann Nelson and James Lindemann Nelson write, "takes its significance from

what has gone before and will go behind. Families are often sites whose significance is

both 'dense' and 'extended'" (80). What others saw in my mother's illness differed from

my view of her experiences of increasing fatigue, pain, and disability. I knew my mother

before cancer. My mother knew me before her cancer. Our volatile conflicts, incompatible

temperaments, and eventual estrangement inform my experience and perspective on my

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[23] The term "first-generation American" can refer to "the first person in a family line to be born in the United States," or to immigrants who become American citizens (Wallraff). I would argue that the same linguistic flexibility also holds for Canadians. However, because I can't imagine a "zero-generation" of Canadians, I use the term, "first-generation Canadians," to mean those who immigrated to Canada (in conversation with Rizwana Jiwa, October 2001).

mother's illness and dying, making them "dense" with filial memories, and "extended" to include our common yet diverse histories as women of colour immigrants in Canada. Writing about my mother necessitates an engagement with our shared yet divergent pasts and my motherless present, with our bodies having moved through and against Hong Kong and Canadian structures.

In this chapter, I will discuss the history of immigrants in Canada, especially Asian immigrants, in order to ascertain the "terms of our entry" (Bannerji, "Popular" 179) and their influence on my mother's pre-illness life and my childhood experiences. Further, I will examine how living as a working-class immigrant in Canada informed my mother's experiences during illness, and how growing up and living in Canada informed my perceptions of her before and after she became ill. Through writing about my mother's illness experiences, I hope to elucidate the complex effects of culture and migration on the embodied lives of immigrants and give testimony to the context surrounding my mother's life with illness. Specifically, I will show how migration affects cultural identity and, in turn, one's sense of entitlement to the resources—specifically, health care—of the "new" country.

> Theory is always written from some 'where' and that 'where' is less a place
> than itineraries: different, concrete histories of dwelling, immigration, exile,
> migration. These include the migration of third world intellectuals into
> metropolitan universities, to pass through or remain, changed by their
> travel but marked by places of origin, by peculiar allegiances and
> alienations.
>
> – Clifford James[24]

As with many Chinese immigrants, my parents' experiences of living in Canada

consisted of working in jobs that the labour market required at particular historical

junctures. Because the Chinese population in Toronto, Canada, was rapidly expanding in

the early 1970s, my parents were drawn to the city for its cultural resources and foods—a

variety of Chinese restaurants, grocery stores, bookstores and movie houses. Since our

arrival in Toronto, my father has worked as a dishwasher at a Canadian diner and as a

cooking assistant at various Chinese restaurants. My mother's jobs, more sporadic and

temporary than my father's due to the demands of childcare, have ranged from sewing

tents and sleeping bags at the Woods® factory to working at fast-food outlets such as

Swiss Chalet® and Gold Chin® Chinese food stalls in mall food courts. My mother chose

to work outside of Chinatown, in places that employed immigrant women with a minimal

knowledge of the English language, such as sewing factories and the food services

industry. My parents occupied historical labour spaces structured for working-class

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[24] bell hooks, <u>Black Looks: Race and Representation</u> (Toronto: Between the Lines, 1992) 173-74.

immigrants. Their jobs required little or no spoken and written English and were often low-paying and non-unionized positions with restricted or no upward mobility.

In recent years, due to changes in immigration policies that permitted people entry into Canada based on economic investment, Asian people possessing substantial financial clout are immigrating to Canada. In addition to the "trade-labourer" and "family-dependent" immigrant categories, there now exists an "investor immigrant" category (Dyck, "Putting" 254). The entrance of affluent Asians—largely from China, Hong Kong and Taiwan—into the management and ownership levels of Canadian businesses disrupts the old nexus: no longer are new Asian immigrants relegated only to working-class trade and labour positions. This marks a departure from the romanticized North American script where immigrants, either as political or economic refugees, leave their home countries with only the shirts on their backs to arrive in Canada eager to labour under gruelling conditions and, against all odds, achieve prosperity. The economic and cultural adjustment of Asian investor immigrants veers off the expected course. These immigrants purchase prime real estate, especially in Vancouver and Toronto.

Some disgruntled Canadians claim that such investments translate into a two-tiered immigration system: preferential status is conferred upon wealthy immigrants, predominantly from Asia in recent years. Conversely, some political activists argue that the new investor immigrant category takes advantage of Asian immigrants desperate to leave their home countries and represents the re-introduction of head taxes in a modern

disguise (Government of Canada).[25] As with the Chinese Immigration (Exclusion) Act of

1885, which imposed a special head tax[26] on Chinese immigrants from 1886 to 1923

(Chinese Canadian National Council 8-11), Chinese immigrants must, once again, pay for

their entrance into Canada.[27] In 1923, the Chinese Exclusion Act was passed to restrict the

entrance of, and, once they entered Canada, to control the movement of, Chinese people;

this act was not repealed until 1947 (CCNC 13). Because of financial investment in

Canada stipulated by immigration policies, Asian people are blamed for inflation, for the

inaccessibility of the real estate market, for monster homes that clash with neighbourhood

aesthetics, for malls lacking English signage—in effect, for not adhering to the "Canadian-

ness" of Canada, and not following the age-old romanticized immigrant script of working-

class assimilation.

My mother existed, and I continue to exist, against this ever-changing landscape of

Asian immigrants and refugees from China, Hong Kong, and other countries. The

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[25] During the years preceding the turnover of the governance of Hong Kong from British to Chinese rule
on July 1, 1997, wealthy Chinese people in Hong Kong were concerned about the economic impact of the
turnover. They sought to move their financial assets out of Hong Kong, and to migrate to other countries.
Coincidentally, the "investor immigrant" class was introduced during these years preceding the Hong
Kong changeover. Investor immigrants come under the category of business immigrants, which also
include two other classes: entrepreneurs and self-employed persons (Government of Canada). To qualify
as an investor immigrant, one must make an investment of $400,000 Canadian, possess a net worth of
$800,000 Canadian (monies must be from legal sources), and provide proof of business experience.

[26] Initially $50, and then increased to $500 in 1903.

[27] While the head tax and Chinese Exclusion Act (1885) limited the number of migrants from China,
European immigrants were solicited and paid by the Canadian government to settle and build an agrarian
base. Some Chinese activists argue that the Chinese head tax paid for the settlement of European
immigrants (Chinese Canadian National Council 8-11). In short, the White European settlement of
Canada was made possible partly through the physical and financial exploitation of Chinese people.

historical traces of this shifting landscape lie rooted in governmental structures and

policies that permitted waves of immigrants and refugees from China, Europe, the United

States (e.g. Blacks escaping slavery, draft dodgers), Uganda, India, Pakistan, Vietnam,

Taiwan, the Philippines, Ethiopia, and a host of other countries. Once here, these same

policies structured the experiences of immigrants and refugees by allocating social spaces,

including labour opportunities, for their arrival and survival. Although my parents and I

followed the assimilationist script into the working class echelons of Canadian immigrant

society, my sense of Canadian belonging is far from secure.

Anti-racist activists and cultural critics such as M. Nourbese Philip have noted that

what we deem public space is often demarcated for particular individuals. In her writings,

Philip criticizes the apportioning of public space for Blacks within Toronto and across

Canada.[28] She likens the increasing police and municipal control over the movement of

Toronto's Caribana parade—a summer carnival which draws an enormous crowd of Black

tourists from across North America and beyond—to the confinement of Blacks within

colonial and post-colonial spaces ranging from 1870s slave ships to current day Toronto,

Canada (Philip, Caribana 27). For Philip, "black skin is not so much a passport as an active

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[28] I use the word 'Black' (capitalized) to denote political identity. In Britain, the word 'Black' is used to assert solidarity between different peoples of colour, including East Asians, South Asians, West Indians, and South Africans. For the purposes of this essay, I will use the word 'Black' to describe people who identify as such in North America, including African-Canadians, African-Americans, and Trinidadian-Canadians. To describe the political solidarity of people from East Asia and South Asia, I will use the word 'Asian'. Within Canadian immigration policies, the image of an immigrant is often that of a working-class person of colour. When I write 'people of colour' or 'immigrants of colour', I do so to acknowledge the anti-racist resistance and solidarity among different ethno-cultural groups. I use the capitalized term 'White' to denote its juxtaposition with Black. Also, I wish to draw attention to and make visible the construction of 'Whiteness' since its discursive power often masks its presence. I capitalize the word 'White' not to suggest any solidarity amongst people regarded as White, but to emphasize and make visible its construction as an underlying category that regulates and measures the proximity to Blackness.

signifier to those manning the borders of the brave new world order of everything that must not be allowed in [sic]. crime [sic], drugs, AIDS, sex, ebola [virus]" (Philip, "Black W/Holes" 28). The bodies of Black people are perceived as contaminated and contaminating; therefore, they threaten the security of Canada's borders and the sanctity of her people. For Philip, the increasingly controlled and limited public spaces allotted to the Caribana parade and festivities represent the fear of Black bodies and the subsequent attempt to contain them. Philip argues that the public regulation and control of Black bodies persists to this day in state practices, such as policing, that regulate everyday public spaces and whose ideological framework traces back to colonialism and slavery.

The fear of Black bodies and Black skin extends to a fear of those who exist beyond the seemingly fragile borders of the Canadian nation, and whose bodies are primarily accepted for their labouring potential. The history of migration to North America includes the journeys of kidnapped Black slaves and the processing of their Black bodies at the borders. Therefore, ideologies around the slave trade must influence how our nation views and organizes immigrants from other countries. Although Canada's history of slavery differs significantly from that of the United States, White Canadians have also participated in human trade. In a House of Commons debate in 1879, Chinese men were compared to agricultural tools, each of whose bodies "we may borrow from the United States on hire and return it to the owner on the south side of the line" (CCNC 5). Immigration thus connotes an importing of labouring bodies, often devoid of personhood in their objectified physical functions.

Within the immigration policies of Canada lurk the nation's overt and covert xenophobic fears. At the Canadian border, people are explicitly judged according to their

countries of origin, their skin colour (darkness) and facial features (Asian), their ability and willingness to fill labour shortages, and their potential criminality and thus threat to national security. In addition, immigrants of colour are often portrayed as vectors of infectious diseases such as tuberculosis, AIDS, and hepatitis. Like Blackness, "immigrantness"—especially if coupled with dark skin—serves as a container for a vast array of negative meanings and fears about national and bodily integrity. Hence, immigrants or refugee claimants may be denied entry based on the perceived threats that they pose to the health and sanctity of the nation.

Notwithstanding the real threat of communicable and contagious diseases, immigration policies of the early twentieth century used physical exams to exclude or detain immigrants—exploiting the conditions of illness and disability and their attendant fears to mask racist discriminatory practices (Whittaker in Anderson and Kirkham 245). Throughout the twentieth century, Canadian immigration policies were not free from pervasive racialized views on physical and mental "fitness."[29] Popular theories of physiognomy and eugenics presented races as quantifiable, genetic and scientific categories (Gould, Mismeasure; Harding; Hubbard; Paul). Despite the current acceptance of race as a social construction, and the increasingly "mixed-race" identities of people descended from parents of different ethnicities and cultures (Rodriguez), the belief that race comprises genetically distinct categories persists to this day.

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[29] The idea of mental fitness, supported by the creation of measurable standards of intelligence through intelligence quotient (IQ) tests and physiognomic theories, was used to deny rights to non-whites, to white women, and to those with psychological disabilities (Borthwick; Gould, American; Lewontin, Rose and Kamin; Tuana). Those categorized "mentally unfit" were denied self-determining autonomy—their decisions were taken out of their hands, and they were infantilized and patronized.

In an examination of the history of Down syndrome, Chris Borthwick cites the racist and ableist preconceptions about racial categories and intellectual development and evolution that underlie its medical classification. As a medical superintendent in a mental asylum, the eponymous Dr. Down "described Caucasian 'idiots' that reminded him of African, Malay, American Indian, and oriental peoples" in his article published in the 1866 *London Hospital Reports* (Gould in Borthwick 3). Because the presence of an epicanthic fold is characteristic of people with Down syndrome and people from the then so-called "oriental" ethnic groups, Dr. Down described the extra chromosomal condition as "mongolism." The misnomer was descriptively offensive to Asians and upheld by prevailing racist evolutionary theories, such as the theory of recapitulation which ranked non-disabled Caucasians at the top of the evolutionary ladder, as a higher and more developed race (Borthwick 3-5). Mongolism represented a condition of genetic "throwback" or "atavism"—stray ancestral genetic material resurfacing after a few generations of evolutionary absence. The creation of Down syndrome as a medical category "racialized" an intellectual disability and "disabled" several non-White, specifically Asian, cultural and ethnic identities.[30]

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[30] Borthwick argues that these misconceptions still operate, so that we view people with intellectual impairments as less developed, either equivalent to children or to "less civilized" people, primarily of non-White ancestry (5-6). We continue to infantilize people with intellectual and psychological disabilities, and—as post-colonial critics, philosophers, anti-racist activists, and feminists add—people of colour and women by denying them political rights and social privileges (Fanon; Mill; Borthwick; Wong). That the social construction of Down syndrome or DS (trisomy 21) may be analogous to the social construction of female gender (XX chromosome), Sophia Isako Wong claims, can be traced to the historical similarities between the medical model of gender and the medical model of disability (97-99). Having grown up with a younger brother with DS, Wong offers a powerful philosophical comparison of the social construction of DS and the social construction of female gender in her reflection on the ethical similarities between aborting a fetus with trisomy 21 (medically classified as therapeutic abortion) and a fetus with XX chromosome (medically classified as sex selection). According to Wong, DS and female gender are

Rather than simply taking offence that Asians are comparable to "White idiots," that people with intellectual disabilities are comparable to "lesser races," or that women, people of colour, and people with disabilities share a history of medicalization as "lesser humans" (Tuana; Wong), we should critically examine how these historical practices pit oppressed groups against one another and deflect attention away from social forces that enforce inequitable conceptions and arrangements. We must focus upon the ways in which immigrants of colour become constructed as vectors of diseases, especially communicable diseases, and as potential drains on limited health care resources. In addition, we should note how race and gender become encoded with attributes of health and disease, where Whiteness and maleness stand in for healthiness, for cognitive and physical fitness or perfection. In contrast, non-Whiteness and non-maleness stand in for disease, physical defect, and mental unfitness. These racial and gender biases against intellectual ability and capacity, mixed with fears of physical diseases and atavism, were pervasive in Britain and her former colonies, including North America, at the turn of the twentieth century, particularly within the overlapping eugenics and birth control movements (Davis, chapter 12; Gordon 163-71).[31] These historical biases influenced what Canadian policy makers sought and continue to seek from immigrants—labouring bodies to lay and strengthen the

interconnected social disabilities: men with DS, like her brother Leo, are feminized because their intellectual disabilities prevent them from meeting the social requirements for masculinity, such as heterosexual agency, independent decision-making, and well-paid employment (113). Conversely, women may be "disabled" by masculinist and medical paradigms that situate them as less cognitively capable than men.

[31] In Canada, Aboriginal peoples were also racialized. For a discussion on the racialization of Aboriginal peoples into "Indians" and "Eskimos," see the chapter, "Race Definition Run Amuck," in Constance Backhouse's book, Colour-Coded: A Legal History of Racism in Canada, 1900-1950.

structural, not the intellectual, foundations of the nation. What we want and expect from immigrants determines how we treat and mistreat them.

Whether at the borders or within Canada, a sense of inclusion or exclusion materializes through government policies that regulate the lives of immigrants, affecting their everyday experiences as refugees, landed immigrants, and citizens. The structure of Canadian society, premised on the two "founding cultures" of the French and the English, has enormous influence on who is unquestionably regarded as a Canadian citizen, and who must struggle for that recognition. To be perceived as Canadian, argues sociologist Sunera Thobani, depends on one's proximity to English or French cultures.[32] Those of us who are unable or unwilling to assimilate by adopting different attitudes, speaking French or English, and altering our appearances (via make-up, cosmetic surgery, or clothing), we may be deemed outsiders, forever at the margins of citizenship. Further, such prerequisites for citizenship favour some immigrants and citizens over others. If the French and English are maintained as founding cultures of Canadian identity, Thobani argues, then people of colour and Aboriginal people—despite their historical and continued presence—will never achieve full recognition as citizens in Canada. People whose ancestral origins are neither French nor English can only come so close to what is definitive of citizenship.

National identities such as Chinese-Canadian and African-Canadian—generally deemed "hyphenated Canadians"—serve to emphasize cultural pride and origins within Canada's multicultural nation, carving out a particular kind of national belonging.

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[32] From Sunera Thobani's talk at a plenary session at the conference, *Making History, Constructing Race*, University of Victoria, British Columbia, Canada. October 24, 1998.

Ironically, such hyphenation also underlines an affinity to "immigrantness," which simultaneously undercuts that very belonging. According to Lee and Cardinal, "[m]ulticulturalism is often seen to be a policy for immigrants, refugees, and 'ethnics'—in other words, those who stand outside of the imagined nation" . Do several tiers of citizenship exist where some Canadians just "are," while some are allowed to belong, and others belong less?

Canadian feminists of colour have written about the Canadian history of immigration and the conceptual construction of immigrants. The project of Canadian nation building, Roxana Ng recounts, involved the differential solicitation of people from different countries to fulfill the national project at the time. People from Ukraine, Ireland and Scandinavia were solicited to travel to Canada to build an agrarian base, while men from China were allowed entry into the country to build the Pacific trans-national railroad (Ng, "Sexism" 234). Once the structural and economic aspects of nation building were underway, the focus shifted to encouraging the emigration of young, White women from Britain for their reproductive potential; nation building was clearly a White British project (235).[33] Hence, Ng concludes, racism and sexism are not just attitudes about race and gender but "systemic: they have crystallized over time in the ways we think and act...and are embodied in the way we 'normally' conduct ourselves and our business in everyday life" (240). For example, we often speak of an "immigrant class" or of "women as an oppressed class" to denote how the forces of sexism, racism and economic exploitation in

[33] At the time, White was defined as British. In her work, Roxana Ng ("Sexism") also notes the changing definition and parameters of Whiteness to include immigrants of French, Italian and Ukrainian descent.

immigrant policies and labour markets affect the livelihood and lives of many immigrants. The preferential and differential reception of immigrants attests to the discriminatory project of building Canada: non-disabled non-White immigrants lay the foundation for and maintain the physical infrastructure of the nation, while non-disabled White immigrants people the country.

This country-building project is expressed in nationalist ideologies, government policies, statutes and constitutions. Immigration trends or "waves," and the subsequent social locations allotted Aboriginal peoples and immigrants, were not accidental but followed a nation-building—and now a nation-sustaining—project that regulated the admission and refusal of immigrants from particular countries of origin and specific histories of dislocation (e.g. political, environmental, and economic refugees). For example, the population growth of European immigrants was encouraged while the number of Chinese immigrants was a source of national concern. The imposition of head taxes and the Chinese Immigration (Exclusion) Act (1885)—both of which drastically limited, if not denied, the entry of Chinese women into Canada—rendered the Chinese Canadian community a bachelor society where the sex ratio in 1911 was 2790 Chinese males per 100 females (CCNC 14). Because the immigrant jobs in Canada were limited to Chinese men (e.g. building the railroad), most Chinese families could afford to sponsor only men but not women. The absence of Chinese women limited the population growth of Chinese communities within Canada (Women's Book Committee, CCNC). In addition, cultural and legal prohibitions against miscegenation prevented Chinese men from marrying and starting families with non-Chinese women (Backhouse, chapter 5). These legislative acts suggest that Chinese people were never meant to populate and inhabit

Canada. Thus, popular views on race and physical and mental health were not without their effects on policies concerning immigration, landed immigrants, and citizenship. As a result, our bodies and their spaces of belonging are continually shifted and interpreted by ongoing and revised policies on Aboriginal rights, women's rights, immigration, multiculturalism, and national security (Lee and Cardinal).

The health and illness of immigrants, especially immigrants of colour, was and continues to be an issue of national focus, often arising in discourses that negatively frame immigrants as potential threats of pestilence, disease, criminality, and political terrorism. Immigrants threaten the physical and social integrity of Canadian citizens. The irony of these discriminatory fears is that colonialists brought widespread pestilence and communicable diseases (e.g. small pox), and unleashed psychological and physical abuse and terror (e.g. residential schools) upon North American Aboriginal communities. The physical dislocation, conceptual erasure, and calculated abolition of Aboriginal communities allowed the illusion of a geographical, social, and political blank slate upon which immigrants could enter to "settle" and "build" a seemingly nascent country without a history of its own. Therefore, an integral issue is not whether immigrants pose any health risks to a country's inhabitants, but, as Philip has observed, *whose* bodies are perceived to pose the most risk and why ("Black W/Holes"). People who pose the most perceived risk (e.g. Black, Asian, and, especially, Muslim bodies since the September 11, 2001 attacks) will be denied entry at the borders, and, once in Canada, will be those most regulated and monitored. Ironically, immigrants must be healthy enough (read: pose minimal health risk) to enter, and healthy enough (read: physically and psychologically capable) to endure the harsh Canadian climates. At best, they are expected to assume responsibility for their

health and well-being. For instance, health promotion campaigns target immigrant

communities, focusing on bringing about a change in personal lifestyles and attitudes

instead of addressing social and economical disparities shaped by ableism, racism, sexism,

and classism (see Dyck, "Health"; Dyck, "Methodology"; see also Krieger and Bassett).

Notwithstanding the availability of state-sponsored health care, this responsibility can be

challenging, given that immigrants must often accept jobs whose hazardous conditions

they cannot control. At worst, their health and bodies become targets of state regulation

(Philip, "Black W/Holes"). In this manner, the presence and residence of some immigrant

bodies appear temporary—they are left to survive, if they can—with meagre support to

sustain their flourishing.[34]

Attention to immigrants and cultural aspects of health, while serving to remedy the

lack of cultural consciousness in the Canadian health care system, can result in the re-

inscription of racist stereotypes. Isabel Dyck warns that studies on immigrant health

should be theoretically and methodologically cautious in order to avoid constructing

immigrants and cultures as static determinants of health care and practice. She writes,

"caution must be used in how the term 'immigrant woman' is interpreted, for it constitutes

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[34] David Wasserman makes an important distinction between survival and flourishing for people with disabilities. He argues that the American with Disabilities Act (ADA) of 1990 is an inadequate vehicle for justice for people with disabilities since it is limited in its scope of what constitutes the necessary conditions for equality (Silvers, Wasserman, and Mahowald). A more comprehensive notion of equality, Wasserman maintains, is necessary for people with disabilities to not only survive but also flourish. The right to flourish expands the notion of equal access to include access to environments that nurture self-respect (192). Equitable access, then, should include access to material needs and immaterial goods such as the opportunity for self-exploration and emotional growth. Survival is connected to physical needs, whereas flourishing implies spiritual and psychological needs. In many respects, immigrants are supported in their survival and less so in their flourishing. What enables immigrants to flourish is often related to cultural resources, usually established or initiated by those immigrants who have come before them, such as cultural associations, religious congregations, and commercial networks that sell culturally sustaining items such as foods, medications, and books.

a taxonomic category that may foster distorted generalizations about women who are immigrants" ("Health" 250). Further, Dyck offers a critique of the culturalist explanatory models of immigrant women's health practices, emphasizing the possibilities of heterogeneity within so-called "cultural communities" ("Putting" 257). Rather than perceiving immigrant women as targets of health education and promotion, we should reconsider what their embodied locations may teach us. What can immigrant women's experiences of living with chronic illness and disability teach us about immigrant health, women's health, medical priorities, and Canadian social values?

B. Immigrant Beginnings: Telling the Past, Living the Present

> What we call the beginning is often the end
> And to make an end is to make a beginning.
> The end is where we start from.
> — T.S. Eliot[35]

On a cold, clear November night in 1972, my parents and I landed in Toronto. A Canada Customs officer stamped our passports: a "landed immigrant" stamp on a piece of paper was affixed to each of our photos. As a child, I shared a passport with my mother. Six years later, we became Canadian citizens. Permitted entry into Canada in the 1970s for the primary purpose of filling labour shortages in those jobs that Canadian citizens had

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[35] Excerpted from section V of "Little Gidding," in The Four Quartets (London: Faber and Faber Limited, 1944).

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refused, immigrants of colour like my mother had to live up to the expectations placed on

the function, willingness, and ability of their bodies. Since immigrants represent a large

reserve pool of cheap labour, the bodies of immigrants may be rendered expendable. Thus,

although many jobs that require hard, physical labour may be disabling, workers may, in

turn, be easily replaced. These views promote labour environments that are detrimental to

the health and well-being of many immigrants.[36] Hence, the category of "immigrant"

appears infused with a distinct racialized conception of disease and health, and a form of

social disregard (mixed with a vigilant, ableist paranoia) for their bodily welfare.

Immigrants find themselves in a tenuous location where their bodies are expected to be

well, at the same time that their wellness does not appear a priority for the state, except

when fears of contamination lead to their monitoring and quarantine.

Pervasive ideologies of individualism and egalitarianism that promote sexist and

racist forms of self-sufficiency inform Canadian social policies, especially ones pertaining

to health care and health promotion. Individuals are expected to take responsibility for

their own health, and women are expected to take responsibility for their own and their

family's health (Anderson and Kirkham; Dyck, "Health"). On the one hand, immigrants

must be vigilant about their bodies and ensure they are not sources of contamination for

communicable diseases such as tuberculosis. On the other hand, they must often labour

within environments containing occupational hazards that compromise their health and

well-being. Immigrant women have the added responsibility of ensuring the entire family's

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[36] Consequently, non-immigrant workers, whose job positions are threatened by the state-facilitated
exploitation of immigrants as cheap and docile labourers, come to find that their health and well-being are
now also expendable.

health with few resources at their disposal. Therefore, the ideology of health promotion, with its emphasis on self-sufficiency, overlooks socially oppressive forces that deny poor and working-class folks, women, and immigrants the ability to control the conditions of their work environments and living arrangements (Sherwin). This structural oversight leads to a "rhetoric of equality" that can skew what are framed as health care problems and solutions for immigrants:

> The notion that equal opportunity is available to all, and that individual effort is responsible for success (Li), is as much a part of the ideology of health care as it is a part of the ideology of other institutions, and it leads to contradictions between what may be seen as a problem and what is proposed as a solution. (Anderson and Kirkham 243)

If the "health problem" for immigrants is presented as a lack of understanding of, or inadequate education on, healthy living, then the "health solution" will be focused on health promotion, and not on legislating and enforcing immigrant workers' rights, providing language interpreter services in health care settings, or scheduling flexible health clinic hours (Anderson and Kirkham 253). Thus, the ideology of health promotion, with its emphasis on how "we do things here in Canada" about health, combines with the physically exploitative conditions of immigrant labour environments to encourage a form of "victim-blaming" (255-56).

My mother and father avoided being dependent upon the state. They shied away from government institutions. They saw themselves as self-reliant immigrants who required nothing but a place to live and raise their children. They worked to avoid blame. In effect, they resisted negative stereotypes fostered by racist and classist representations of immigrants in media and government policies that portrayed immigrants as lazy and dependent on social handouts. Instead, they preferred the "good immigrant" script. As

Asian immigrants, the good immigrant script was more available to them than to immigrants from other regions and continents, such as Jamaica or Africa, whose blackness resulted in greater discriminatory fears. Stereotypes of visible minorities, Himani Bannerji argues, are "images of ascription and prescription" ("Popular" 180). They grant a particular form of visibility whose imagistic narrowness and rigidity reinforce the absence of other images. For example, popular images of South Asian women as silent, docile, unclean, and smelling of curry circulate and then are continuously recycled as a kind of common knowledge about them, preventing other images that may represent diversity or plurality (179). Within these narrow representations, the visibility of "visible minority" women is measured against what is invisible and thus "normal." What constitutes their visibility makes them "more visible" (181-82), or what M. Nourbese Philip calls "hypervisible" ("How White") and "provides the content of...[their] racist experiences" (Bannerji, "Popular" 179). Since it is impossible to divest oneself entirely of stereotypes, one is forced to choose what one believes is the more benign one. Often, being a good immigrant leaves immigrants open to exploitation, and enables others to exploit them, by scripting them as willing to labour under any condition and as masochistically self-sufficient. Conversely, being a bad immigrant could mean actively challenging exploitative conditions and fighting for one's rights within Canada at the risk of being viewed as ungrateful or a discredit to one's cultural community.

To be a good immigrant, however, necessitates an understanding of what comprises a bad immigrant in order to avoid being one. As a child, I overheard my parents disparaging Chinese co-workers who—in contrast to my parents' resilient self-sufficiency—seemed to want and seek out all available social benefits. I imagined their co-

workers as greedy and ungrateful immigrants who would one day be found out by the government and punished. Bad immigrants are those who reportedly "cheat the system." Or so the bad immigrant (and bad welfare recipient) script goes. I wonder if my parents' avoidance of social benefits, of interaction with government agencies, represented a fear and suspicion of the state—the threat of deportation or retaliation. I do not know the particulars of my father's employment in Chinatown restaurants, except that he had no extended health benefits, worked ten-hour days for six days a week, and did not have vacation time unless he was laid off for a few weeks. For many uneducated immigrant labourers like my father, there exists an underground economy full of employers who hire workers without reporting them to the government, avoiding taxes for both employer and employee—often touted by employers as "tax-free" money that benefits workers. However, such an arrangement denies workers job security and safety. These "unofficial" jobs—sometimes the only ones available to uneducated, working-class immigrants, and some of which can be found in Chinatowns across Canada—make immigrants ineligible for the state's social benefits, such as worker's compensation for work-related injuries and unemployment insurance coverage, and decrease the entitled amount of their government pension upon retirement.

Although my mother's jobs were with larger companies outside of Chinatown that presumably paid taxes and unemployment insurance, her employment history was sporadic due to childcare and job dissatisfaction. In contrast to my father, who made friends at his workplace, my mother appeared not to enjoy working. Several times, she complained to my father that her co-workers or bosses treated her badly. Since my mother did not work within the Chinese community, she was more likely exposed to racist and classist sexism.

For my parents, being good working-class Chinese immigrants involved complex processes of negotiating available employment, accepting the rules of the social benefits system, and maintaining a sense of independence from the state, whether by default or intent.

As a child immigrant, my experiences differed significantly. As a four-year-old child, I was entitled to receive free education until the end of high school. The education system ensured my acculturation, since I started my Canadian education at the same time that other children were entering the public school system. After high school, my parents and relatives assumed I would attend university. My high school was full of immigrants and children of immigrants. It was an unspoken and spoken assumption that we would go as far as our academic standings could take us. Like many students in my high school—located in an inner-city multicultural and working-class neighbourhood—I wanted a post-secondary education that would guarantee well-paid employment. I had educational and employment opportunities my parents did not—opportunities my parents gave me by immigrating to Canada. My father's elementary education was interrupted by the Japanese invasion of China. My mother's Hong Kong education ended just before high school, because she had to find paid work. After graduating as a pharmacist, my first job in a hospital pharmacy allowed me to earn double my parents' combined annual income. Before then, I had never fully appreciated the economical disparities between "educated" and "uneducated" jobs.

Child immigrants and the children of immigrants stand to gain more than adult immigrants, because our youthful entry into the Canadian system allows us time to adjust and learn social and cultural mores, to adapt values and attitudes. In the most basic yet

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complex way, my parents' lives made mine possible. Does the value of their lives sustain

and inform mine? As a pharmacist working in a multicultural, working-class, and

politically leftist neighbourhood, and as a student in a university graduate program, my

work involves a re-evaluation of my parents' lives, especially my mother's life. As a

Chinese immigrant woman, how did my mother's life fit into the Canadian economies of

trade, and cultural and intellectual discourses? In order to assign value to my mother's

illness experiences, I must consider the value of her pre-illness life. Unlike some who

arrived with more money and a higher education, my mother embodied the classic

immigrant script, yet she did not prosper as much as the immigrant myth purports. Instead,

like many immigrants across this country and around the world, she lived a quiet life,

raised children, paid taxes, and left a legacy for her descendants to decipher. My mother's

death left me to make sense, and theory, out of our experiences.

Feminist writers with working-class backgrounds—including Carolyn Steedman,

Audre Lorde, bell hooks (Talking Back; Killing Rage), and Kath Weston—have used

experiential narratives within academic spheres to counter the myth that working-class and

uneducated folks cannot theorize and do not read theory. The revaluation and inclusion of

working-class experiences in academia challenge the classist, racist, sexist, heterosexist,

and elitist parameters of pedagogy. Because education was and continues to be perceived

by some as a tool for assimilation, many immigrant, working-class, Black, and Aboriginal

parents affirm the value of education to their children, while simultaneously warning them

of its danger (hooks, Talking Back 98-99). Having lived through the racial desegregation

of public schools in the United States, bell hooks writes that her Black working-class

parents emphasized the importance of education while warning her that being smart did

not mean one became superior to others (99). When I graduated from grade eight with the school's top honours, my mother attended the ceremony. Instead of congratulating me, she told me that awards mean nothing, and insisted that I was no better with them. Her warning, or perhaps fear, of yet another layer to our growing estrangement looms in my graduate work. Did my mother want me to achieve the pragmatic results of an education—that is, a good job—without the often classist and ethnocentric indoctrination of academia?

Mixed messages about the value of education placed me in a position familiar to many who become educated "beyond" their working-class or cultural locations. Education not only distanced me from my mother, but also, in some respects, from what my mother represented: working-class woman with an elementary level Chinese education and limited facility in English. Education offered me a place for self-examination and achievement away from home. Now, I turn to the academic sphere to theorize my way home, to find my mother after her death. My mother's immigrant life was not without purpose. Her life, combined with generations of immigrants, forged present-day Canada—their bodies peopled this nation as they made new lives for themselves, which, in turn, made Canada a new country. As an academic, my task is to carry on my parents' legacy of making this country and myself anew, to work backward and forward with historical and lived experiences. In my beginning is my end.[37]

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[37] The first line of the poem, "East Coker," by T.S. Eliot, The Four Quartets (London: Faber and Faber Limited, 1944).

C. Childhood as Immigrant, Illness as Immigrant: Uncertain Lessons and Embodied Paranoia

A few months after my mother's death, I sit in a dark and empty theatre and gaze at the screen as colours and shapes slide in and out of focus. The camera languidly pans across objects in a room, across the traditional Chinese "cheong-sam" dress that clings to the curves of a famous Hong Kong actress. Yo-Yo Ma's cello emanates a sonorous lilt as my eyes feast on the reconstructed aura of 1960s Hong Kong saturated with Wong Kar-Wai's dimly lit sets and lazy panoramic views of rooms and bodies. Tony Leung's form-fitting black pants and skinny black tie, along with Maggie Cheung's *cheong-sam* and upswept beehive hairdo, remind me of the Hong Kong pictures of my father and mother during their courting period, and at their wedding banquet. My parents wander the streets of this film. Hong Kong before my birth. My parents before they were parents, when they were a man and woman walking toward their futures. Through this film, I meet them in their past.

Since our emigration from Hong Kong thirty years ago, only my mother had returned, to attend a funeral. My view of Hong Kong lies in my imagination, and in the representations I glean from films and music. I question friends who maintain ties with Hong Kong, ask them what the city is like—the sights, the sounds, the smells. Mostly, I hear about the pollution, the crowded streets, and the immense stress of living in a fast-paced and crowded environment. What I know of my parents' Hong Kong "pre-immigrant" existence lies in these imaginings. I worry that my representation of their lives

will appear simple and shallow, buying into and reinforcing the culturalist fantasy of difference and the historical traces of a former British colony.

Having arrived here with my parents at the age of four, I am more Canadian than anything else. Nevertheless, I feel as if I do not belong in Canada, as surely as I cannot, after a thirty-year absence, claim Hong Kong as mine. A sense of belonging is necessarily problematic for immigrants, whose lives traverse geographical regions and bridge cultural traditions. In their journeys, immigrants interpret their new countries with experiential lenses shaped by their former homes. Many times, I feel like a participant-researcher in a feminist ethnographic study of Canada (Reinharz)—jotting down observations in my dual consciousness as insider (Canadian-educated pharmacist and academic) and outsider (immigrant woman of colour with working-class roots). An unsteady oscillation between belonging and not belonging suffuses my Canadian identity.

In a critique of neo-conservative portrayals of feminists and immigrants as threats to national integrity, Lee and Cardinal claim that the idea of a universal Canadian citizenship is a myth, because multiculturalism policies have positioned immigrants, especially women of so-called "ethnic minorities" and their cultural practices, outside the national project . For example, the educational space allotted to, and the teaching accreditation required for, non-English and non-French languages, such as Japanese and Swahili—deemed heritage languages outside of official school curricula and often taught by women who are their native speakers—indicate how multicultural policies can situate languages and their speakers as "unofficially" and "officially" Canadian. Multicultural policies are constitutive of the "structuring dynamic" of the hegemonic nationalism that imagines feminists and immigrants outside "Canadianness," while simultaneously

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containing them within it as subjects of "difference" and "diversity" (218, 221-22, 229).

Thus, Lee and Cardinal (1998) conclude:

> The concept of citizenship has been reformulated in terms of categories of identities and linked to nationalism, which deploys race, gender, ethnic, linguistic, cultural, and other markers to classify and organize peoples into different hierarchically structured categories of citizenship, thereby justifying and allowing for differential treatment of groups seen as "non-national." (223)

Immigrants of colour, often perceived as "non-national" outsiders with conflicted loyalties to other countries and nations, possess tenuous claims to national interests and citizenship. For immigrant women of colour, whose gendered socialization leads them to assume responsibility for ensuring ethno-cultural transmission to children and for maintaining family and ethnic traditions, their nationalist sympathies and thus citizenship are particularly suspect. Does my embodied uncertainty of my Canadian citizenship—my unsteady oscillation between belonging and not belonging—approximate what my mother experienced as a Chinese immigrant woman living with metastatic breast cancer?

During my initial trips to Toronto after her cancer metastasized to her lung, I drove and accompanied my mother and father to her many examinations and chemotherapy treatments at the oncology hospital. Each time, we usually spent a full day at the hospital, mostly waiting for doctors to appear or test results to manifest. For us, hospital time was composed of long, seemingly endless hours of sitting in waiting areas and, after my mother was called to change into a hospital gown, in small examination rooms. These slow and silent stretches culminated in intense, brief, and informationally-packed minutes with oncologists, residents and interns. As my mother's condition worsened, the minutes of waiting seemed to accrue with the slowing of her movements,

due to fatigue and breathlessness. In her company, time's measure moved through and with her. Time itself seemed to cease its forward motion. It had been years since we had last spent so much time together. Once, while I was alone with her in an examination room, we ended up talking about nothing in particular. This rare break in silence pushed me back in time. I fell into a younger self. Later, I wrote in my journal:

> On good days, the cancer releases its grip on her and she breathes
> momentarily without sweat. Fine unseen filaments reach across her lungs,
> suppress her breath's desired expansion, her push for a taste of this sweet
> spring air. We sit staring at the windowless walls of a hospital examination
> room. We are inaccurate figures amongst neat squares and perfunctory
> circles of tables and chairs. I roll across the room on a small round stool,
> propelling myself and spinning as if in the Toronto diners she used to take
> my brother and me when we were kids. There, we learned Heinz® ketchup
> and French fries; we learned that the cherry red seats spun with the
> strength of small hands gripping the counter for the push off. I spin and roll
> through space.

When I was a child, my mother was the cultural filter through which I savoured Canada. We circled the supermarkets outside of Chinatown, picking up Libby's® canned spaghetti and Swanson® frozen dinners to bring home to our pots and oven. At the department store cafeteria, we sampled fish and chips, lettuce and tomato salads, and red Jello® with stiff, nickel-sized dollops of cream. In the corner diner beside the Chinese cinema on Queen Street, we sat in red vinyl booths and ordered hamburgers and French fries, flipping the selections on the jukebox as we waited for our food. In my adulthood, my mother became the lens through which I viewed bodies changing with age, illness, and dying. She was the medium through which I sampled the harsh flavour of breast cancer— its sickeningly sweet liquid nutritional supplements, its bland and soft foods, and its inflamed tongue and dry mouth.

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Although I had interned and practised as a pharmacist in an oncology hospital, and then at a community pharmacy near an HIV clinic, I did not fully appreciate the ramifications of cancer and other life-threatening illnesses on people's lives until my mother was diagnosed with breast cancer. While accompanying my mother to medical appointments, and while waiting for her prescriptions to be filled at the pharmacy, I gazed at the white lab coats flowing swiftly through hospital corridors and behind dispensaries, and saw myself captured and reflected in that busy professional veneer. My mother's reticence around doctors and nurses, along with her uncertainty around changing bodily symptoms and the medications supplied to aid them, made me acutely aware of how health care workers interacted with her. She seemed lost and overwhelmed, and, when accompanying her, I too felt clumsily awkward and out of step with the hustle of the medical workday. To reorient myself, I became her pharmacist and managed her treatments. Either in person, or through phone calls, I facilitated the exchange of information between various medical specialists and my mother: signs, symptoms, expected outcomes of procedures, therapeutic risks, and side effects. Even as her pharmacist, however, I could not stop being her daughter, and, on what became monthly, albeit short, trips to Toronto from Vancouver, I witnessed her discomfort and confusion within the vast expanse of the health care system. Her experiences with cancer caused me to see myself finally, as a daughter and pharmacist, and note the distance I had maintained in both roles.

Emotional and physical distance has always been a tangible entity between my family and me. For a few years in high school, I lived away from home at my mother's insistence. The summer before the start of my university education, after yet another

heated conflict with my mother, I left my parents' home. Distance translated into a familial

measure and tempestuous substance; our relationship became marked by conflicted

absences. Since then, I have orbited the gravity of my family's relational dynamics. I met

them only for birthdays, and the occasional holiday. I rarely saw relatives who lived in

town. I was not in contact with any out-of-town relatives. Unlike my brother, who has

always lived at home except during his semesters at an out-of-town university, I had

grown, throughout the years, into a stranger. As the older of two children, I had battled

for my independence—a common occurrence for the oldest child in most families. When

my mother's breast cancer metastasized to her lung, I was living in Vancouver and

studying in a graduate program. Although I had lived away from home for over ten years,

my mother's terminal illness pulled me back into the thick of familial conflicts and

interactions.

In November 1999, my mother's cancer recurred. She called me. Tests showed

lung metastases. She had suspected something was wrong. Laboured breathing. During

her September trip to New York. My cousin's wedding. She could not understand. Why

had cancer returned to her while other women remained cancer-free? I fell silent, could

offer no reassurance. When I spoke to her oncologist, he gave a poor prognosis. The

cancer was causing fluid to accumulate in her pleural lining—the thin membrane cradling

the lung that eases its movement during breathing. The pleural fluid made breathing

difficult and painful. I asked him, "How long?" He hesitated in circumscribing a time

frame, but, because I lived across the country, he finally said she could survive several

months to a year, or two. I was not sure if my family realized this or what each member

wanted to know. In conversations, my brother—six years my junior—pushed for

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experimental immune therapies, for the newest of the new. Unsure of whether this was his

way of coping, or whether he was seeking a miracle cure, I mentioned that experimental

trials were few, and that our mother probably did not qualify. More importantly, because

our parents did not have private medical insurance, high-priced innovative treatments with

unproven efficacy were financially out-of-reach. As it stood, my mother's expensive

medications were already being covered by a drug plan offered by the provincial

government to aid the working poor.[38] Because my brother was emotionally closer to my

mother than me, I often wondered if I was the indifferent fatalist to his wishful optimist.

In my family, I am the outspoken one who questioned medical treatment,

protocols, the wherefore and why. My mother often said, "Mm ho gum bah-biy." Don't

make a fuss. Or, more accurately, don't mess it up with your fuss. Over the Christmas

holidays, the chemotherapy caused my mother's white blood cells to drop and she was

admitted to the hospital. When she was discharged a week later, she called me in

Vancouver on New Year's Eve. Tearfully, she told me that she had overheard the nurses

gossiping openly about her just outside her hospital room. They did not like her, had

called her a "problem." She vowed never to return to that hospital. "That hospital" was

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[38] In 1994, the Ontario Drug Benefit Program, which subsidized medication costs for seniors over the age of 65 and for people on social assistance, expanded its coverage to "people with unmanageable drug expenses" through its Trillium Drug Program (Trillium Drug Program brochure 1997-98). In Ontario, AIDS and social activists had long rallied for comprehensive government drug coverage for the working poor, and for those whose illnesses contributed to their impoverishment. Before the Trillium Program, people without private medical insurance had to exhaust their life's savings and lose their properties to purchase life-sustaining medications, especially those with AIDS and chronic illnesses such as cancer, whose medications cost in excess of thousands of dollars per month. Only after they depleted their savings and no longer owned their homes or any property did they qualify for social welfare assistance and government coverage for their medicine. Practicing as a pharmacist in a working-class neighbourhood bordering the gay ghetto in downtown Toronto, I witnessed people's struggles against illness and poverty. Fortunately for my parents, my mother's need for expensive chemotherapy medications did not begin until after the start of the Trillium Program, and their life's savings and home were spared.

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the oncology hospital where she had been treated throughout the years of her illness. When my brother got on the phone, he sounded angry and wanted to call my mother's doctors. I tried to mediate the situation from across Canada, soliciting details from both my mother and brother. Once more, I played the big sister. I tried to negotiate their anger and, as the conversation progressed, stave my increasing frustration at their unwillingness to be pro-active about their complaints. How long could I support them from such a geographical and emotional distance? And was this was something I even wanted to do? Growing up, I had always been the cultural interpreter for my parents and brother, and thus was often the one to get things done—the problem solver. Or so I had thought that was why they came to me. Looking back now, perhaps all they had wanted was an understanding ear.

Unlike my brother, I did not take my mother's complaint at face value. My mother had always been a private person, and had attempted to control what others knew about her. As a child, I was commanded to say nothing about my mother around relatives. If pressed, I was told to lie. If I let slip any information, I was punished physically. I learned to mind words and taste their potential betrayal. Speech was tangible, possessed of physical weight and danger. My mother seemed preoccupied with ensuring that others did not talk about her. Knowing what I knew that New Year's Eve, I had wondered if my mother, in her vulnerable state of lying in a hospital bed, had purposely eavesdropped on the nurses' conversations to make sure they were not talking about her. In that scared and possibly paranoid state, she may have misheard the collegial banter of nurses.

A few months later, my father called for an ambulance in the middle of the night, because my mother was having difficulty breathing. At the time, I was in town staying

with friends while my brother was out of town for his university studies. I found out the next afternoon when I called my parents' home. When I arrived at the local general hospital, she had just been moved from the emergency ward to a room on the inpatient oncology floor. The admitting nurse asked several questions, and I served as the translator. When the nurse left the room, my mother turned to me and asked why the nurse called her a "problem." I looked blankly at her. What? When? Then it dawned on me: the nurse had asked me if she had *problems* breathing. Did my mother expect nurses to automatically resent their patients? Was she afraid they would make her return to the oncology hospital she so desperately wanted to avoid? *Mm ho gum bah-biy.* Afraid she had inadvertently made a fuss. Afraid she had already messed up the care that she needed. Here, in Canada, she did not have to tip health care workers—unlike the Hong Kong public hospital where she had given birth to me over thirty years ago. She did not have to pay money to hospital staff in order to avoid bad attitude or mistreatment. In Canada, the currency was uncertain and the price unclear. Perhaps she thought that if she complied with medical opinion and the directions of hospital staff, they would reward her with a good prognosis and withhold any resentment of the care they had to provide her. Was this what she knew about surviving? I worry that, in attempting to be a good immigrant and a good patient, my mother lived with the burden of thinking herself a burden.

In his book, The Wounded Storyteller, Arthur Frank proposes that many people living with chronic illness and/or disability experience an "embodied paranoia" of medical institutions (172). Often, they are suspicious of those very institutions that provide the medical treatment and care they seek and require, because they often find their physical vulnerability and emotional fragility exacerbated by the bureaucratic organization and

environment of medical structures. The faceless bureaucracy of medical systems reinforces the impersonal and depersonalizing effects that can demoralize and disempower ill people and make them compliant to structural rules and regulations. Yet, impersonal and depersonalizing processes and effects of medical systems can, to a limited extent, enable health care workers to treat patients fairly and equally (Zussman in Frank, Wounded 147). For instance, a beloved public figure and a heinous murderer would arguably receive the same care within an impersonal and depersonalized environment. However, such environments also transform individuals into generic "patients," silencing unique voices and ignoring particular experiences of suffering (Frank, Wounded chapter 7). The contradiction is that while one receives specific care for one's particular survival, one is simultaneously made to feel indistinguishable from others receiving care. Furthermore, medical treatments themselves may initiate and/or contribute to a host of illnesses, which medical epidemiologist call iatrogenic diseases. Since cancer chemotherapy treatments— more so than the cancer itself—cause a great deal of suffering and pain, it is not surprising that some people wonder if chemotherapy is therapy or torture (173). When treatments appear more painful than the condition itself, when the medical system works to keep people alive while simultaneously depersonalizing their experiences and denying their voices, paranoid feelings are more than justifiable.

Admission into a hospital often represents one's inability to survive without medical intervention; thus, one is literally at the mercy of those whose knowledge and skill can support and heal her or him. In many respects, a patient may want to stack the odds in her or his favour so that doctors and nurses will want to care for him or her more than the others. To be a stellar patient. To charm hospital staff. To ameliorate one's embodied

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paranoia, especially when hospital bed shortages, cuts in provincial health care budgets, and the ensuing "burnout" of medical workers increase workplace stresses, which can contribute to errors of omission and commission. How may one vie for the best possible care in such an environment? through passive agreeability? through a friendly demeanour? Bonnie Sherr Klein observed that "[w]hen you are dependent like that, if you alienate any of the staff you are really helpless" (192). Klein felt helpless despite the fact that her husband—a prominent medical doctor practicing at the Canadian hospital in which she had received care after her stroke—had wielded significant influence on the nature and direction of her medical care. Through the advocacy of her husband and her wide network of family and friends, Klein gained a certain status among hospital staff. As did Marilyn French, who wrote in her cancer narrative: "my reputation preceded me in my [American] hospital stays: most of my doctors knew I was a writer, knew I had a certain repute: I was treated as a person of status. The situation for people without status was very different" .

My mother did not have doctors in her immediate family, she was not famous or rich, nor did she have numerous people advocating on her behalf. As a socially isolated immigrant woman, she had little status within the various Canadian hospitals she entered. Unlike Klein and French, she did not have access to many strategies or important people to ameliorate any feelings of insecurity. What she could and did do was to be a compliant and placid patient. Her hospital visits and stays were anonymous and quiet. She preferred to have no visitors, except for my father, brother and me. True to her private personality, she kept her cancer to herself, forbidding us to tell anyone in the family about her illness. No relatives or friends of the family knew until a few weeks before her death, when she finally permitted my father to inform her half-sister who lived in town, the sibling closest

to her. Towards the final months, my mother's prolonged absence from family gatherings and her unwillingness to speak to relatives on the phone had generated a lot of speculation and concern. Unable to reach her, relatives questioned my father, brother and me. To honour her wishes, we flatly lied.

Once again, my mother enlisted us to defend her privacy; however, this time the details were not about her life but about her dying. Already a relatively guarded person, my mother must have experienced feelings of embodied paranoia, especially during her increasingly frequent, and then final, stays within hospitals, where little privacy could be maintained. However, I imagine that her limited grasp of the English language, combined with her scientific illiteracy, must have intensified that illness-related paranoia, or given it a different shade when mixed with the cultural uncertainty, if not paranoia, of being an immigrant. Despite her twenty-plus years of acculturation to Canadian customs and systems, she had to struggle to comprehend her body within a scientific discourse that she never had an opportunity to learn. How did she "get" cancer? How did it come back? In my ineloquent combination of Cantonese and English, I fumbled with translation—did not know the words for cells and lymph nodes—and ended up with rough ink sketches on the back of a wrinkled store receipt. Did she feel more illiterate and uneducated in the presence of health professionals and medical technicians who usually did not speak Cantonese yet understood her cancer? Did living with cancer affect the way she saw herself as a Canadian citizen, as a Chinese-Canadian immigrant?

Over the years, my mother underwent chemotherapy and radiation treatments in an inner-city Toronto hospital, applied for social assistance to cover the costs of her expensive medications, and rode the public transit system alone, to and from her medical

appointments. When she was still able to live at home, she qualified for home care: a nurse visited her after hospital discharges, and a care attendant visited to bathe her and perform housework. She was not able to continue her quest to be a good immigrant citizen who needed no handouts, no government assistance. Perhaps, she imagined that she could avoid others' scornful pity if she never asked for social assistance. Having started from a position of not interacting with the state, of keeping to herself and guarding her privacy, my mother became submerged in state-assisted and thus very public aspects of health care and social assistance. Moreover, because of her illness and increasing physical weakness and anxious confusion, she found herself in a position of needing help from non-Cantonese-speaking strangers—people whom, if she were not ill, she would probably not readily admit into her life. My mother appeared grateful for the health care she received, smiling weakly at health and hospital workers. Did she feel responsible somehow for her illness and for what she did not know? I step in as the daughter and witness to contemplate my responsibilities to my mother's memory. Had she been one of those countless, nameless working-class immigrant women who silently nod and smile, waiting for their bodies to be attended to by health care workers?

D. Memoir of Nobodies

In her book, <u>Landscape for a Good Woman</u>, Carolyn Steedman recounts her working-class childhood and that of her mother to illustrate the complexities of working-class consciousness in post-World War II England. Citing Simone de Beauvoir's

description of her mother's death from cancer as being relatively "easy," Steedman compares it with her own mother's death from cancer. While de Beauvoir's mother died an "upper-class death," Steedman's mother, who had "lived alone...died alone: a working-class life, a working-class death" (Steedman 2). But what about the period before their deaths? Steedman imagined that cancer must have seemed the final injustice to her mother, whose life had been full of hardship and unfairness (1). Did Steedman's mother experience a working-class illness and death, since she lived alone with few, if any, caregivers around? Did de Beauvoir's mother experience an upper-class illness, an upper-class death with servants and paid and unpaid caregivers attending to her needs? If one is financially secure and endures little hardship, then suffering during illness may seem an unexpected and intolerable occurrence. If one's life had been circumscribed by financial hardship and suffering, then suffering during illness and disability may seem a familiar and brutal addendum or conclusion.

Unlike Britain in the 1950s, in Canada today, the differences between the experiences of an upper-class life and death and the experiences of a working-class life and death depend upon factors other than and in addition to birthright, accents, and inherited property. Factors such as ethnicity, cultural identities, immigration, class mobility, educational opportunities, and access to social services contribute to various permutations within the class structure, and, hence, affect how we experience the complexities of class. Thus, I will extend Steedman's analysis to incorporate immigrant experiences. My mother's death reflected her working-class life: an immigrant life, an immigrant death. While Steedman examines the experiences of her mother's working-class life and aspirations from a psychoanalytic perspective in order to shed light on gender and class

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consciousness, I look to my mother's experiences of cancer and dying for an understanding of the effects of migration, gender, class, and race on illness. Steedman's mother frequently told Steedman and her sister that she was a good mother, one whose working-class ethic enabled her to feed and shelter them. Similarly, my mother strove to be a good immigrant woman, one whose resilient immigrant ethic enabled her to survive and raise her children in a new country. In her own time, place, and class system, each endeavoured to be a good, working-class woman, in life and during illness.

As a child, I often heard my parents and relatives say, "At least you have your health." This phrase was often used as consolation for financial worries or emotional loss. For many people, especially working-class immigrants with physically demanding and, frequently, non-permanent jobs, one's health is necessary for labour and survival. The phrase "at least you have your health" was their way of saying, "It could be worse." For a working-class immigrant woman with little education and a limited grasp of English, my mother's life could have been worse. She could have had to labour in sweatshops, inhaling dust and fabric lint in windowless rooms for over twelve hours a day, like many other Asian immigrant women. But then, it could always have been worse, or gotten worse. My parents knew that life was hard, yet they did not want to complain. "Moa bahn faat," they would say with a resigned sigh. No other way. In their outspoken refusal to complain, in their admitted refraining from airing grievances, I heard their sad acceptance of fate. What happens when the very least (i.e. health) that you could have is no longer yours? When the basic minimum with which you had been consoling yourself disappears? My mother's body, with its ability to labour, was the premise upon which she entered this country:

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physical labour in exchange for Canadian citizenship. When she was diagnosed with cancer, did she feel that the exchange had been thrown off balance?

Writing about his earlier years in medical practice, physician and poet Rafael Campo observed, "[T]hose who were marginalized...seemed especially susceptible to illness.... But back then, all I knew was that poor patients said very little and almost never asked questions" (182). One's sense of entitlement to health care and other social services reflects one's sense of security within the nation. Or, one's sense of entitlement may mirror one's comfort with, and knowledge level of, government systems and medicine. Poor people, people who have little access to education, working-class immigrants and refugees, people of colour, Aboriginal folks, women, queer and transgendered folks, and socially marginalized people often live with expectations (their own and others') that they should be grateful simply to live in Canada and receive whatever care and assistance the medical and social systems dispense. During my mother's illness, I too was grateful for the financial and medical assistance she received. I was relieved that my father and mother did not have to lose their home, or all of their savings, to treat my mother's cancer and alleviate her suffering. Thankfully, I did not have to forego my personal and financial plans to care for my mother. The social safety net shifts historically according to demands and needs. Therefore, I remain indebted to social activists, AIDS and cancer activists, and others who gave witness to illness, because their experiences and actions resulted in social programs and cultural support networks that made my mother's experience of being an immigrant woman with cancer less difficult for her and for me.

Unlike Audre Lorde (Cancer), Arthur Frank (At the Will), and Barbara Rosenblum, my mother did not possess the cultural tools, resources, desire or energy to

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write her illness narrative. Her limited grasp of the English language combined with her scientific illiteracy left her struggling to comprehend her own body. To remedy this, she kept a precise record. A small tattered notebook always lay within her reach. Within its pages, in meticulously neat handwriting, she recorded each tablet she took, what tests she'd had and when. Within these pages she composed and recorded her body. When she became too weak and confused to write, she instructed my father to continue for her. Initially, my father dutifully recorded what she instructed, but her increasing forgetfulness and morphine delirium left him agreeing to her wishes while leaving the notebook unmarked. As her condition worsened, my mother forgot about her notebook. When she died, I too had forgotten about the notebook until after my father had thrown her belongings out, without consulting my brother and me. In a pragmatic sense, her notebook helped her answer the usual questions that health care workers asked when taking her medical history. Yet, I imagine that through her careful recordings, the overwhelming number of tests, treatments and tablets became more manageable, and her experiences, more comprehensible. In retrospect, I wonder if I should have protected that notebook from the trash, kept it as a testament of my mother's attempt at order in her world of increasing disorder. Unlike Sandra Butler, who was Rosenblum's primary caregiver and co-narrator of her illness experiences, my father did not save my mother's writings, nor did he have the resources to narrate their experiences of her illness.[39] While my mother is

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[39] A few months after my completion of chapter three and during a visit with my father, I asked if he remembered the notebook in which my mother had written her tests and medications down. He nodded and looked away, said he still had them. She'd had more than one. He said he'd kept some things with her writing in it, including a few birthday cards and her notebooks. "That's great," I said with surprise and a sense of overwhelming gratitude. Since my mother's death, my father has occasionally offered me the

not the typical working-class Asian immigrant woman, that her illness experience went

unrecorded and unpublished could be described as typical for many immigrants.

In her book, Reconstructing Illness: Studies in Pathography, Anne Hunsaker

Hawkins examines the relatively recent North American phenomenon of illness stories as a

form of autobiography or memoir or, more specifically, as a combination of pathology and

biography she calls "pathographies." Drawing from the works of Sigmund Freud and

Oliver Sacks, she defines pathography as "a form of autobiography or biography that

describes personal experiences of illness, treatment, and sometimes death" (Hawkins 1).[40]

By calling illness stories *pathographies*, Hawkins emphasizes the embodied narrator

whose story is gleaned from the minutiae of biological and physiological processes and

disorders. Illness stories mark a unique departure in life stories or biographies: the

narrator's experiences of bodily functions and processes explicitly establish the plot and

drive the narrative consciousness. According to Hawkins, writing and bearing witness to

illness are tasks usually undertaken by educated, upper- to middle-class people, especially

if they are famous or rich. She indicates two voids in the genre of pathographies: a)

narratives by marginalized folks; and b) narratives by physicians and health care workers

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mementos he'd thought important and had saved including her jewelry, and her birth certificate and passport. I've declined some and accepted others. For now, the notebooks remain in his possession. I don't feel a need to see them, but savour the idea of their continued existence.

[40] In her footnotes, Hawkins cites the influence of Sigmund Freud and Oliver Sacks's conceptions of pathography on her work. For Sacks, *pathographies* are "biographies that combine science and art"; he refers to Freud's case histories as exemplars (Hawkins 177). According to Hawkins, Freud's examination of Leonardo Da Vinci employs the term *pathography* to refer to "a biographical study that focuses on the way pathological elements in a person's life can illumine other facets of that life" (178).

that do not uphold or perpetuate a medical stance (160).[41] As a pharmacist bearing

witness to her mother's illness and death, I potentially straddle Hawkins's two stated

voids. However, despite Hawkins's suggestion that more illness narratives by marginalized

folks are needed, there continues to be wary resistance from academia and the reading

public. In an age where personal tragedies are exploited for sensationalism, and where

people vie, on television and in print, to shock viewers and readers by divulging intimate

details about their lives and bodies, we have reached what literary theorist Tom Couser

sardonically, yet seriously, observed as an "age of memoir," replete with the "ascendancies

of the nobody memoirs."[42] According to Couser, people who have lived socially

unimportant lives can now write and publish self-aggrandizing memoirs, due to relatively

inexpensive computer publishing software and technology, alongside the proliferation of

"vanity presses." Within Couser's comment lies a critical question: what's the point? Some

feminists have argued that sometimes the personal is just personal and not political. Is my

narrative about my mother's illness experience a "memoir of nobodies"? a socially

unimportant daughter writing about her socially unimportant mother? Throughout history,

women and other marginalized folks have traditionally been social nobodies, whose lives,

achievements, and thoughts have gone unrecorded and ignored. Yet, what makes someone

a "social nobody"?

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[41] For examples of point b, see the narratives by Rafael Campo, Oliver Sacks, and Abraham Verghese.

[42] Discussions took place during the "Panel on Narrative Ethics" with Tom Couser, Hilde Nelson, Susan
Wendell, and Marjorie Stone (chair), at the *Narratives of Disease, Disability and Trauma, An
Interdisciplinary Conference*, May 9-11, 2002, University of British Columbia, Walter H. Gage
Residence, Vancouver, B.C., Canada.

My mother's illness experience differed significantly from that of people who were able to write about theirs. There were few books in my childhood home. Sometimes, there were newspapers or Chinese magazines about Hong Kong celebrities. I rarely saw my mother write anything for a prolonged period of time. She wrote short notes, and greetings in Christmas and birthday cards. A few times, I saw her reading a book. My mother did not become a breast cancer activist after her diagnosis, nor did she become a volunteer at the Canadian Cancer Agency. She did not attend breast cancer support groups. When offered counselling resources, she declined; she said she did not need to talk, that she could just watch television. She did not gather her friends and family together to allow them to learn about illness and cancer through her experiences. She did not have an academic forum in which she could theorize her illness experiences. She did not possess what Frank defined as a "communicative body," the ideal body for bearing witness to illness (Wounded 40, 48, 52, 163-65; see footnote 20, chapter 2). Cancer was something she had never wanted, and she did not integrate it into her identity.[43] She wanted to be alone with cancer. She often sat staring into space, unable to read or watch television; occasionally, she listened to her small radio. She wanted her family to be alone

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[43] In one sense, my mother did integrate her experiences of cancer into her identity by continuing to guard her sense of privacy. However, in the realm of identity politics wherein marginalized identities are reclaimed, my mother—unlike Audre Lorde, Barbara Rosenblum, and the women described by Barbara Ehrenreich—did not make cancer or any other part of her social identity (e.g. Asian, working-class) the focus of her illness-related struggles. She did not embrace the "cancer survivor" identity that Ehrenreich (Welcome) describes as saturated with a cheery volunteerism and pink kitsch. Yet, she also did not challenge the cosmetic superficiality of breast cancer survivorhood that Audre Lorde (Cancer) did in her assertion that a breast cancer survivor is a warrior woman and not one who simply needs make-up and prostheses (see discussion in chapter two). I imagine that my mother, as an isolated Asian woman, perceived cancer as her private affliction. From our past conversations, I got the sense she wanted out of cancer—to get her cure and go, to never have to talk about or encounter cancer again.

with her in her cancer. We were not allowed to tell anyone who knew her that the cancer had recurred, that it was terminal. When she became too weak to walk, she refused to go out in a wheelchair lest the neighbours see her fragile state. Several times, I suggested telling relatives, because I was worried about my father—the primary caregiver without any outside emotional support. Each time, my mother refused. My father said he had to honour her wish. My mother's illness experiences appeared as uneventful and unremarkable as her isolated and quietly private life. In her personal and cultural isolation, my mother was a model "social nobody."[44]

Two particular factors distinguished my mother's position as a "social nobody": financial constraints and socio-cultural insecurity. They led to her lacking a sense of entitlement to health care and other forms of assistance. Together, they were encapsulated by two of my mother's oft-repeated phrases, which summarized well her outlook and actions during her life and illness: a) "mm ho gum bah-biy" (don't make a fuss); and b) "moa bahn faat" (there's no other way). In many respects, these two sayings typified her illness experiences. *Moa bahn faat* represented her stoic outlook on her past and present circumstances. It was a phrase my father used increasingly as my mother's condition deteriorated. It was his way of saying we did what we could, and we are doing all that we can. Often, doing everything we could was limited by how much money we could realistically spend on what she needed and wanted. *Mm ho gum bah-biy* represented her

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44 However, like many immigrants to Canada, she enabled her children to have educational and life opportunities they would not have otherwise had. As a result, I can, as her daughter, narrate her illness experiences in a context where they can be appreciated and valued. What made my mother a "social nobody" can also make her into a "social somebody" in different contexts, in changing times—especially if she had been a nobody due to oppressive social forces. This will be discussed in chapter four.

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sense of decorum and her fear of incurring others' wrath and disapproval. Sometimes, *mm ho gum bah-biy* overlapped with *moa bahn faat* when she felt disappointed with, yet resigned to, the care and time that health care workers did and did not give her.

Although my mother did apply to the Trillium drug program (see footnote 38) for social assistance with medications, she did not readily admit her need. She shook her head when I first asked about her financial situation. At the time, she was not employed, and my father's work contracts had become fewer and farther between. After months of persuasion and over $1,000 spent on medications, my mother finally filled out the application form. In addition to prescription medications, my mother consumed Chinese herbal tonics purported to help bodies weakened by cancer. She drank less than the recommended dosage, because the tonic was expensive and its efficacy was unproven. She reasoned, however, that every little bit would help. A few small vials of the tonic cost $50. She also ingested herbal capsules that cost $40 per bottle; a Hong Kong movie star claimed they helped fortify the body during cancer. When she lived at home, my mother's hospital visits to the downtown oncology hospital from her suburban home cost over $50 return in cab fare. Relatives and friends who owned vehicles could not offer rides, because my mother did not tell them about her illness. Neither my father nor brother had ever learned to drive a vehicle. When I visited, I rented a car. Without private insurance, the one time they called an ambulance, they were charged $60 upon admittance to the hospital. Each time my mother was admitted into a hospital, it cost a flat fee of approximately $15 to activate the phone in her room.

During one of my visits a few months after her cancer metastasized, she said to me in a conspiratorial tone, "Your father doesn't give much consideration to what he cooks

for me. The food is always so hard." At the time, my father had become her full-time caregiver. He rarely slept through the night, because my mother often called out for him every few hours. During the day, he cooked their meals, shopped for groceries, and ran household errands. Occasionally, after my brother had returned home from work in the evening, my father went out to meet friends. I discussed the possibility of Meals on Wheels, and arranged for the local Chinese seniors community centre to send them Chinese meals. After some persuasion on my part, it was agreed that two meals would be delivered to them, three days a week. The Meals on Wheels service cost $120 per month. I purchased a $150 cell phone for my parents. My father carried the cell phone whenever he left the house. It allowed him to be out of the house for longer periods without adding to my mother's anxiety. She felt better knowing she could always reach him.

When my mother's cancer recurred, my father had just retired and was receiving a government pension. Because of my mother's terminal illness and my father's retirement, my mother qualified for income assistance. Fortunately, my parents had finished paying the mortgage on their home a few years before. Without the provincial drug program that covered my mother and father's (coverage extended to spouses) medications, I imagine that my parents would have lost their home and all their savings. Even with the various levels of social assistance, a large part of my mother's savings went toward costs associated with her illness and death (e.g. Chinese herbs, transportation, cemetery plot, and funeral arrangement). When a family member or someone you love is dying, you would like to think that you would spare no expense for her or his survival. However, as working-class immigrants, as people with limited finances, my father, brother and I could not claim that money did not matter. We did not go into debt to try to keep her alive. We

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did not fly her to the United States, to Europe, or to Mexico for experimental therapies or miracle cures. We could not afford alternative practitioners and treatment modalities, except for the occasional herbal remedies. Money mattered, as it always has, in our survival. Money, especially its lack, left me feeling helpless. *Moa bahn faat.* The money we did not spend on her was not the sum of how little we loved her. As Barbara Rosenblum and Sandra Butler realized, the gift of money does not easily translate into love, and the withholding of money does not necessarily signal a lack of love. Yet, our guilt surfaced with the awareness of all that we could not give or do for her.

The phrase "mm ho gum bah-biy" has different meanings. In some contexts, it can mean, "don't be sassy" or "mind your own business." When I was a child, I thought it was a remonstrative phrase to warn me that I was "out of place"—that I had left the expected parameters of obedience. During my first visit to Toronto after her cancer recurred, my mother chided me with "mm ho gum bah-biy" after I had asked the nurses about her condition and her medications. She did not want to stir things up, thought I was making more work for the nurses or giving them attitude. In the realm of the hospital, she was a child again who had to be careful not to go "out of place" or step "out of line." Similar to people with disabilities who find themselves feeling "out of place" and, yet, compelled to stay "in place" within inaccessible public spaces (Kitchin 345), my mother felt insecure and paranoid.[45] She was worried that I would get her into trouble with the doctors and nurses.

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[45] Disability studies scholar Rob Kitchin proposes that the structure of space, particularly inaccessible physical environments, reflect the biases of those who build and maintain that physical space. Certain places and spaces exclude people with disabilities for the very reason that they have not been imagined to

She did not want their anger and resentment. *Mm ho gum bah-biy*. Near the end of her

life, my mother spent just over a month in a palliative care unit where other hospital

residents yelled and moaned loudly and fearfully into the night. My mother told my father

that she too wanted to yell into the night, but that she was now so weak, she could barely

make herself heard. Now that she did not want to be quiet, she could not be loud.

A few weeks before her death, she spoke with the Cantonese-speaking hospital

chaplain about her dying wishes. In that conversation, she expressed her sadness around

the conspiracy of silence that surrounded her own mother's disappearance and death when

she was only three-years-old. My mother's mother was the second wife of a polygamous

Chinese businessman. When that businessman took a third wife soon after my mother's

birth, my mother's mother was so enraged that she ran away and was never heard from

again. She left my mother, her only child, behind. When she was a teenager, my mother

asked the first and third wives and their family members for details about her mother, but

no one would tell her what had happened. A week before her death, I met with my

mother's half-sister, the youngest daughter of the first wife, and relayed my mother's last

wish: to learn what had happened to her mother and where she had been buried. My

mother died before my aunt could obtain the details. *Moa bahn faat*. After her funeral, my

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use and access such areas. As such, people with disabilities often experience space as structured and organized to keep them "in their place" or to ensure they feel "out of place" (Kitchin 345). Hospitals, like many other public institutions, can structure space so that the people who occupy those sites behave in certain ways. For example, those seeking care are labeled patients and assigned charts and hospital gowns, and are restricted to certain areas. On the other hand, hospital workers wear uniforms and can access all staff areas, in addition to patients' areas. The regulation of space mirrors the power systems at work within structures and organizations. These ideas within disability studies build on and echo feminist, anti-racist and post-colonialist analyses of power dynamics within public and private spaces.

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aunt told me that no one knew what had happened to my maternal grandmother. *Mm ho gum bah-biy.*

A composite of familial origins, local circumstances, personal beliefs, and historical context contributed to my mother's experiences of cancer, shaping her resistance against, and stoic acceptance of, painful and difficult situations. "Each woman," observed Lorde, "responds to the crisis that breast cancer brings to her life out of a whole pattern, which is the design of who she is and how her life has been lived. The weave of her every day existence is the training ground for how she handles crisis" (Cancer 9). My mother's sense of motherlessness, combined with her migration from Hong Kong and her experiences within the immigrant women's labour market, among other factors, shaped her unique yet all-too-common profile as a "social nobody." Given that there are more nobodies than somebodies in society, it is probable that my mother's illness experiences are more representative of those in the general population than those of a "social somebody." In this respect, nobody memoirs of illness may provide important insight into cultural phenomena. They can show how experiences of oppression could have been worse, or how they could be made better, during times of illness.

Because my mother was not famous, not rich, not literate in English, and preferred her solitude and privacy during illness, her "uncommunicative" body was constrained in its ability to bear witness to illness. If, as Frank proposes, "[b]ecoming a communicative body is an ethical end, a telos, for a life to aspire to…[and if] the communicative body is not a fixed state but a *recursive process*" (Wounded 163-164; original emphases), then my mother's limited opportunities hindered her process of realizing her body and thus my process of bearing witness to her illness (165). Because of personal choices and social

limitations within my mother's immigrant life, I step in as the witness to transform her constraints into avenues for my openness. This is my response to the crisis of my mother's breast cancer and death. It comes out of the whole design of how I have lived my life as a pharmacist and graduate student, as an estranged daughter working and mourning her way forward.

Chapter IV

Telling Us: Ethics, Embodied Relationships, and Identity Reparations

As discussed earlier in the narratives by Audre Lorde (Cancer), Arthur Frank (At the Will; Wounded), and Sandra Butler and Barbara Rosenblum, the act of bearing witness to one's illness through writing enables: a revaluation of suffering, self-conscious living, a confrontation with culturally imposed silences, an assertion of or a dismantling and then rebuilding of one's identity and beliefs, ethical relationships that manifest through dialogical interactions, ethical wills that offer experiential paths along which others may embark upon their own journeys, and a means through which experiences can be given meaning. Unlike these ill narrators, my mother did not write an illness narrative due to personal and historical circumstances. Instead, I wrote down what I'd witnessed of her illness experiences, drawing from my journal writings and mental notes.

My mother appeared to embody the opposite of what Frank called a "communicative body"—his definitive ideal for embodied witnessing. Yet, she was not necessarily "non-communicative" (Wounded). She talked about her hospital stays and kept a precise record of her examinations, medical procedures, and medications. As a working-class immigrant Asian woman with limited education, my mother focused her energies on trying to understand breast cancer and on surviving with dignity. As for many working-class immigrants, the dissemination of her illness story depends upon someone "skilled in giving voice to those who in our society so often remain voiceless" (Hawkins 160). As her Canadian-educated daughter, I witnessed her illness in the context of being a pharmacist and a graduate student working on a thesis about illness narratives. As a woman of colour student in the academy, I inhabit the margins of a privileged space. Although I can bring my mother's illness experiences to the fore, I question my ability to give voice to her voicelessness.[46] Had she been able, my mother would have told a different story of her illness. *Moa bahn faat.* No other way. Or she would have scoffed at the thought of even telling a story. *Mm ho gum bah-biy.* Don't make a fuss. What I can offer is my intimate witnessing of her illness and an analysis of the literary strategies and personal conflicts of that witnessing. My story of my mother's illness is partly a memorial, a requiem, a vehicle for mourning, a defense of her life, and a defense of illness narratives.

In this chapter, I will interrogate my witnessing of my mother's illness experiences, setting its shape and content against the backdrop of other illness narratives and against the academic analyses of illness narratives as a genre of biographical writing that counters

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[46] See previous discussion in chapter one about the problem of speaking for others.

culturally dominant myths about bodies. To do this, I will first discuss the paradox of

being a social nobody whose voice is ignored yet in demand. What does it mean when we

tell or hear stories of illness? How are tellers and listeners implicated in narrative processes

and expectations? Second, I will continue the discussion from the previous chapter on

Arthur Frank's proposal that an ill person's particular and changing relationship with his

or her body and with others gives rise to different narrative content and strategies

(Wounded). Illness narratives can poignantly illustrate how social mores, cultural

influences, interpersonal relationships and historical roots mediate and form our

embodiment and embodied relationships (see Butler and Rosenblum; Lorde, Cancer;

Frank, Wounded; Frank, "Illness"). Lastly, I will examine how popular cultural metaphors

and symbols are embedded within one's representational repertoire, and thus within one's

experiential narrative of illness (see Meyers; Sontag). Cultural metaphors and symbols are

encoded within "master narratives," or culturally dominant stories that describe and set the

stage for social and interpersonal relations (Nelson). Illness stories can reinforce master

narratives, such as medical ones that describe illness in the language of symptoms and

cures. Or, in some cases, illness stories can move beyond the medical paradigm and

challenge the language and content of master narratives. Illness narratives that counter

master narratives, that challenge the status quo, can serve political and ethical purposes

through their potential impact on the identities of people living with illness and disability

and their intimates.

Due to growing literacy and accessibility to tools for literary production and dissemination in North America, the act of writing and publishing one's memoir no longer signals the importance of the writer or the written work. In the not-so-distant past, when literary production and formal education were reserved for the privileged few, we would less likely encounter what Tom Couser wryly called "nobody memoirs."[47] Presumably, only socially important people possessed noteworthy experiences and observations. Marginalized folks who were poor, non-white, queer, disabled, and sick had to struggle against social structures that upheld unequal power relations and mediated their experiences—the effect of which was the prospect of being labeled "nobodies" in their time and by future historians. Hence, in this contemporary period where educational and literary tools—such as textbooks, novels, paper, and computers—may be accessed by those with less privileged social backgrounds, many writers must address the "nobody" labels that dog their lives and literary work. The ability to write one's story no longer distinguishes the writer as socially privileged or the tale as socially important.

In former times, an author might "beg pardon of the (usually) aristocratic patron-reader for taking up her or his time" (French 242). Historically, literary works, memoirs included, were not only usually written by "somebodies" but also commissioned by them. Being a "somebody," however, does not grant one unrestricted authority to write about

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[47] See footnote #42 in chapter three.

unpopular topics that counter prevailing cultural norms and symbols—such as the experiential value of illness and disability, which counters myths surrounding physical strength and perfection. Even the well-established, contemporary feminist novelist, Marilyn French, felt insecure about audience reception of her illness narrative. Although writers no longer beg pardon for taking up the reader's time, French wondered if her narrative would be construed as an imposition: "[A]s I finish this book, I feel a need to ask the reader's indulgence for my long recital of personal ills. I feel uncomfortably like someone who obsessively subjects others to hours of description of her latest operation" (243). French's narrative hesitation and anxiety are precipitated by cultural mores that place illness—and any other evidence of bodily weakness or frailty—into the private and personal realm, while publicly celebrating bodily feats of strength and invincibility, often depicted as someone's ability to overcome or exceed the body's usual limits.[48]

Because illness narratives, as a genre of autobiographical writing, delve into experiential details about embodiment and suffering, there is more than the "nobody" label to be overcome. Illness is not a lauded achievement nor is it commonly imbued with any experiential value that warrants literary merit. On the contrary, illness symbolizes a host of failures—of the self (poor diet, high stress, lapsed judgment about one's physical limits,

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[48] In her book, The Rejected Body, Susan Wendell explicates bodily ideals and standards, proposing that bodies are feared for their unpredictable and all too-common departure from physical and functional ideals of beauty, strength, and sexuality—all of which are erroneously presumed to be under autonomous control. For people living with illness and disability, bodily ideals combine with myths of bodily control to increase self-doubt and isolation. As a result, individuals with non-ideal bodies (i.e. sick and disabled) come to be contemned as unable and/or unwilling to control their bodies (Wendell, Rejected chapter 4).

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inability to "read" one's body) and of others (misdiagnosis, toxic treatments, bad genes). Illness highlights one's culpability for physical vulnerabilities in the framework of one's responsibility for one's body. Also, since illness may cause discomfort, suffering and pain, it draws attention to the negative aspects of one's embodiment and, consequently, to one's physical vulnerability and mortality.

In the history of western thought, bodily weaknesses and ailments are typically viewed as liabilities for the person, whose essence or spirit is postulated to lie within a physical cage of flesh and bones (Grosz 3-9). As a site and source of experience, including physical suffering and pain, the body is viewed as a means through which one can express and attain spiritual passion and enlightenment. Although one's essence presumably lies within a noncorporeal spirit, one's body is imbued with value, since the body is regarded as an instrument to express, and a mirror to reflect, spiritual virtue and vice. Thus, ideas about morality map the body. Illness and disabilities come to represent physical or psychological failures of control or moderation, which in turn, are attributed to spiritual defects (Sontag; Wendell, Rejected). Hence, Elizabeth Grosz argues that a "profound somatophobia" informs the foundation of western philosophical thought—defining the body as a "source of interference in, and a danger to, the operations of reason" (5). Somatophobia, which Elizabeth Spelman defines as a "fear of and disdain for the body" (Spelman 126), reifies the intellect and debases bodies. According to Spelman and Grosz, somatophobic thinking has led to: the dualistic conception of "mind over body"; fears that the body will betray the mind (as the locus of reason); and in Christian tradition, the separation between body and spirit (or soul). Hence, narratives of illness symbolize a double negative: bodies are emphasized within a somatophobic realm, and negative

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embodied attributes and experiences, such as pain and suffering, are detailed. Regardless of one's social status, writing about one's illness experience is discouraged. Nonetheless, a social nobody would meet relatively more resistance than a social somebody in narrating his or her illness experience. Who would grant an audience to a socially unimportant person telling a tale about a devalued experience?

What makes one a social somebody or nobody, however, is inextricably bound to the history of somatophobic thought. The dichotomous conceptualization of body and mind influenced definitions of gender, race and class. Social theories were formulated within, and reinforced by, biased descriptions of all non-whites, white women, slaves, and working-class folks as hostage to their bodily processes and physical desires; thus, as many dubious social arguments went, these "bodily-driven" folks are intellectually inferior and hindered in their capacity to reason (Spelman 126-127, 131-132).[49] Androcentric scientific and philosophical theories reduced women to their bodily functions and, compared to men, imperfect organs and physiology (Tuana). White women were portrayed as hostages to their anatomy (especially their uteruses) and female hormones. Not only did women have more uncontrollable physiological urges, but their inferior

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[49] In his article, "Racism, I.Q. and Down's Syndrome," Chris Borthwick offers an insightful discussion on the inter-locking biases threading through definitions of psychological disability and race. In the article, "IQ: The Rank Ordering of the World," R.C. Lewontin, Steven Rose, and Leon J. Kamin point out that I.Q. or "intelligence quotient" tests are comprised of questions requiring culturally-specific knowledge, often available only through formal education. By default, individuals lacking that particular knowledge—primarily, people from non-white races, or those who could not access educational resources—came to be defined overwhelmingly as intellectually inferior (Gould, American; Lewontin, Rose and Kamin) and, consequently, as Borthwick demonstrated, intellectually "disabled" against the scale of white supremacy. See the discussion in chapter three.

bodies also made them more susceptible to these urges. White men's capacity to reason, on the other hand, allowed them to overcome and master their physiological urges.

As discussed earlier in chapter three, racist descriptions and theories that ranked Asians as members of a primitive "lesser race" enabled white medical experts to construct Down syndrome as an intellectual disability attributable to a "genetic throwback" to Asian-ness (Borthwick). Furthermore, racist conceptualizations eased the historical exploitation of Asian male immigrants to Canada, who were relegated to work in specified areas of manual labour, such as building railroads (Chinese Canadian National Council 6-7). At the same time, Chinese women were denied entry to Canada via quotas and head taxes; thus, in concert with the implementation of miscegenation laws, the Chinese community became a "bachelor society." As a result of the partnership of immigration and socioeconomic policies, an "immigrant class" was created wherein race, gender, class, and sexuality systemically coalesced (Ng, "Sexism"). Thus, somatophobia fuels our understanding of illness and disability, and shapes social concepts and categories such as race, gender, class and sexuality.

Moreover, becoming ill or disabled can transform a "somebody" into a "nobody," since people living with illness and disabilities often lose their jobs, become impoverished due to medical expenses, receive insufficient social and financial support, and live in physically inaccessible and socially isolating environments (Silvers, Mahowald and Wasserman; Wendell, Rejected). Unlike social categories of race, class, gender and sexuality, however, the definitions of disability and illness are based in part upon

impairments that can be "inherently unpleasant or difficult" (Crow 209).[50] That is, while cultural, racial, feminist, and queer resistance can transform devalued bodily experiences (e.g. skin colour; menstruation; sexuality) by purposefully celebrating them, people with disabilities and illnesses can't easily celebrate some bodily experiences (e.g. pain, immobility) that are inherently difficult. Thus, complex processes of finding value in experiences of illness are often central to illness narratives, as evidenced by Audre Lorde's (Cancer) reclamation and celebration of her scarred post-mastectomy body, Barbara Rosenblum's construction of her narrative as an "ethical will" to teach her family and friends about living self-consciously with illness, and Arthur Frank's (Wounded) assertion that experiences of suffering possess social and ethical significance as a form of embodied testimony that teaches us how to relate to one another through our shared physical vulnerability. These authors emphasize that illness as an experience and not simply as an identity marker or medical condition is what merits storytelling. As the popular saying goes, "It's not who you are or what you have, but what you do with who you are and what you have that counts." In many respects, then, illness and disability share commonalities with social categories such as gender, race, class and sexuality in that their concepts are historically informed by somatophobia, and their forms of anti-oppressive

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[50] Liz Crow argues that the social model of disability emphasizes the social construction of disability to the point of erasing impairment. Such a position, Crow claims, is politically unwise for it neglects impairment—the basis upon which discrimination may be claimed and compensation awarded. In practical terms, the "onus will remain upon disabled people to prove discrimination" (Crow 224). In other words, replacing biological determinism with social determinism in the model of disability is not the answer. Instead, Crow advocates an anti-essentialist view that resists deterministic moves and equally addresses disability and impairment. This point is particularly poignant in experiential narratives of illness and disability, which illustrate that suffering and pain—while exacerbated by environmental stressors, inadequate nutrition and social isolation—do have an organic source in damaged tissues and nerves (Lorde, Cancer; Mairs; Wendell, Rejected). See also footnote #10 in chapter two.

resistance mirror and build upon existing political strategies of reclamation and revaluation. For example, people "come out" about their illnesses and non-apparent disabilities, just as gays and lesbians "come out" about their sexualities, in order to embrace their illness- or disability-marked bodies, as Audre Lorde (Cancer) did by refusing to wear a prosthesis after her mastectomy (Hillyer chapter 8; Wendell, Rejected chapters 1 and 2).

Illness and disability can also be distinguished from social categories like gender and race, in that people can and usually do become sick and/or disabled as they age while they don't usually become another gender or race (Wendell, "Old Women"). Barbara Hillyer compares disability to queer sexualities, because both involve a sudden or prolonged transition from a privileged identity (e.g. non-disabled, straight) to a more stigmatized one (e.g. disabled, queer). Notwithstanding that some people are born with disabilities and chronic illnesses, and that some people claim to have been born queer, neither sexuality nor disability are entirely stable categories for individuals. Some queer folks describe their sexuality as in flux or fluctuating. Some people living with disabilities, such as American actor Christopher Reeve, talk about future cures for spinal cord injuries. Research-oriented charitable foundations for cancer and diabetes solicit funds to "search for the cure."

On the other hand, the categories of race and gender appear immutably fixed at birth. In recent years, however, transgendered, inter-sexed, mixed-race and anti-racist activists have challenged the immutability of gender and race. I don't wish to downplay the potential for suffering and pain with illness and/or disability. Nor do I wish to represent illness and disability as simply social categories. However, I do want to

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emphasize that illness and disability are similar to social categories (e.g. class, gender, race, and sexuality) in that they are socially significant embodied phenomena. Moreover, processes that enforce marginalization, whether based on race, gender, disability or illness, interact and intersect; thus, they should be studied in concert and not in isolation. Illness narratives, including Lorde's (Cancer) and Butler and Rosenblum's, often espouse the revaluation and reclamation of several marginalized identities wrought by interlocking processes of social domination.

The recent proliferation of illness narratives—whose popularity has resulted in the establishment of the illness narrative or pathography as a genre of autobiographical writing—indicates a growing cultural interest in experiences of illness, suffering, and healing (Hawkins). As discussed in chapter three, two pathographical voids currently exist: stories by marginalized folks or so-called social nobodies, and stories by health care workers who don't employ the medical stance (Hawkins 160). As in other discursive spaces, the voices of marginalized ill folks tend to be absent. Hence, my narrative of my mother's experience of illness as an isolated, working-class immigrant woman with a minimal grasp of the English language—which would have garnered little notice or concern in the past—would now be of special interest. Because of the social marginality of my mother's life and my marginal place in academia, my narrative of my mother's illness could potentially challenge the various and interconnected terms of our marginalization. Hence, the study of illness narratives should be contextualized not only within the realm of autobiography but also within the realm of "counterstories," or stories that challenge culturally dominant "master narratives" that support and perpetuate unequal power relations (Nelson; to be discussed later).

The proliferation of experiential illness narratives stems from the overall growing interest in marginalized voices—due in large part to the work of feminists, social and disability activists, queer activists, and critical race theorists, who have criticized the dearth of self-representation by marginalized folks. Feminists, especially feminists of colour, whose praxis underscored the viewpoint that "the personal is political," established arenas where marginalized folks could gather and hear themselves and each other. Despite the increased demand for marginalized voices, Sherene Razack has observed that stories by socially marginalized folks can be used to further their domination, or be used as a form of voyeuristic entertainment (101, 17). Razack describes the "internal dilemmas" experienced by marginalized folks when they step up to tell or are asked to tell their stories within classroom settings (117). The urge to tell one's story is countervailed by its potentially disrespectful reception as entertainment, as raw material for theoretical construction by white and/or male academics, or as proof of one's marginality and subjugation (109-110). Stories may be used to prove that some cultures, especially those deemed "third world," are patriarchal and backward (e.g. in sexual politics or technology). Equally, the urge to refrain from telling one's story, to avoid judgment, or to avoid telling at the wrong time also poses problems. With silence, does one reinforce the stereotype of a passive Asian or a quiet and long-suffering black woman? While the internal dilemmas of self-representation explicated by Razack are not new or uncommon, what has shifted with the advent of identity politics and post-modern critiques of subjectivity is that one's ascension to the status of "somebody" can be undergirded by one's claim to being historically a "nobody." In other words, one's story is significant because one's voice has been historically suppressed and denied. In a similar vein, one's story becomes important if

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one's experience has been historically suppressed—such as illness, disability, or queer sexuality. At this historical juncture, it is not surprising that storytellers and listeners are wary of the potential for exploitative and/or narcissistic accounts, and of burdensome demands to perform or listen.

Storytelling for the purpose of critical reflection within academia is problematic, because the academic setting is not divorced from socio-political arenas. As a woman of colour academic trying to implement critical pedagogical practices within her classroom—including creating classroom space for marginalized voices, and using personal experiences and storytelling to challenge academic knowledge production—Roxana Ng is acutely aware that academia cultivates and embraces an environment whose privileges and values are confluent with social, economic and political ones (Ng, "Teaching" 147-48). Hence, exchanges within the classroom mirror the unequal power dynamics mediated by oppressive social structures, which enforce sexist, racist, heterosexist, classist, and ableist biases that confer merit and attendant benefits upon the privileged few.

Who people are outside of the classroom influences who they can be inside the classroom. This is evident in the ways in which individuals behave or speak, the stories they choose to tell or withhold, and their abilities to listen and hear others. If you are a social nobody outside the classroom, then you will speak as, or be asked to speak as, a social nobody within the classroom. However, the power dynamics shift in complex ways when a racial minority female teacher, as Ng identifies herself, attempts to insert critical pedagogical practices within the classroom ("Teaching" 135-39). Since Ng is a woman of colour professor, the academic setting does not offer her a position with as much unquestioned authority and expertise as that of white male professors. If she introduces

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critical teaching into her classroom, of which one of the tenets is a critique of professorial authority, then she may be undermining what little authority and power she may hold. The practice of critical teaching does not unproblematically create a subversive learning environment. No matter how critical the pedagogical practice, then, the classroom does not strip or cleanse students and teachers of their identities—everyone enters with their social privileges and disadvantages.

For marginalized folks, "[t]he strategies of empowerment, dialogue and voice do not in fact work as neatly as they are supposed to because there is no unity among the oppressed and because our various histories are not left at the door when we enter a classroom to critically reflect" (Razack 109). However, for many marginalized folks, critical pedagogical spaces (e.g. some classrooms) may offer them rare opportunities to voice their experiences, and to hear about other marginalized experiences. Because marginalized folks have few spaces in which to speak, they may feel compelled to tell their stories whenever the opportunity arises, even in situations where their stories may be exploited or used against them. Hence, when listening to, or writing about, "nobodies," one must criticize the structural and historical processes and institutions that privilege particular people and experiences while pronouncing other people and experiences socially insignificant. When we consider the historical processes that permit or deny marginalized voices, we can better appreciate that, under disempowering conditions, remaining silent and speaking out may be two sides of the same coin. Therefore, writing about a conventionally negative experience, such as illness, can compound the internal dilemmas of the socially marginalized storyteller by causing her to further second-guess herself and the

audience. Could illness make a "nobody" noteworthy? Could one's "nobody" status make one's illness significant? In which case, is one merely a "tokenized token"?

While Razack offers no clear-cut solutions to the narrative dilemmas she identifies, she does recommend that we break down the dichotomy of storyteller versus listener in order to better appreciate how we often occupy both, if not multiple, positions with respect to stories (118-21). In addition, she calls for us to consider the reasons why we tell and listen to stories, and how these stories function in different arenas, such as classrooms, law courts, and everyday interactions. Ultimately, stories affect the lives of tellers and listeners; therefore, our actions and intents around stories have ethical implications. Thus, my narrative of my mother's illness, and the illness narratives by Lorde (Cancer), Frank (At the Will), Butler and Rosenblum, must contend with several layers of cultural resistance and demand that foster conflicting narrative urges and hesitations, and lead to uncertain and unpredictable reader reception.

In their narratives, Lorde (Cancer), Frank (At the Will), and Butler and Rosenblum succinctly conveyed their attempts to organize and create meaning out of their illness experiences. Similarly, in my narrative of my mother's life with breast cancer, I attempt to organize my memories and create meaning out of her illness experience. I interpret my mother's working-class immigrant life before and during her illness in order to make sense of her illness experience and of our past interactions, and, in doing so, to revalue her immigrant life in Canada. To a certain extent, by telling my story of her illness, I can explain and justify my actions during her illness—decisions made, words exchanged, and money spent or withheld. Moreover, because we live in an age where, as Tom Couser charges, memoirs can be used as one of various vehicles for self-aggrandizement or

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exploitation, my story of my mother's illness must embody a defensive affirmation of this narrative form: I must prove the value of my mother's life in order to prove the value of my witnessed account. Furthermore, I must interrogate my narrative intentions to understand my ethical obligations and responsibilities as an intimate witness. Why would a daughter narrate her mother's illness? Am I trying to bestow value on her experiences? Or am I exploiting my mother's suffering and death to advance my nascent academic career? How has telling this story shaped the woman I am, will become?

B. The Communicative Body: Constraints, Intents, and Reciprocity

> Understanding the meaning and significance of a story requires
> understanding how it is communicated within or against specific cultural
> discourses and through specific narrative strategies and linguistic practices.
>   – Susan Chase[51]

Guy Widdershoven and Marie-Josée Smits argue that stories are teleological, possessing both descriptive and prescriptive elements that convey a narrator's sense of meaning and structure. "By telling stories," they assert, "people interpret their actions and justify them toward each other" (Widdershoven and Smits 280). This teleological aspect of narratives generates relational dynamics between the narrator and the subjects of the stories, and between the narrator and the audience, wherein ethical considerations about

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[51] Susan E. Chase, "Personal Vulnerability and Interpretive Authority in Narrative Research," Ethics and Process in the Narrative Study of Lives, ed. Ruthellen Josselson (Thousand Oaks, CA: Sage Publications, Inc., 1996). 55.

representational accuracy or truth come to the fore. How we tell a story—details we include or exclude—entails representational decisions and strategies. The details I disclose about my mother's illness experiences involve my understanding of, and my attempt to respect, my mother's sense of privacy, as well as an acknowledgment of my father and brother's memories of her—all of which are tempered by my endeavour to ensure factual and emotional accuracy. What we choose to reveal obscures undisclosed details; what issues we emphasize mask other equally relevant concerns. Even though it may appear self-evident that narratives are stories that people tell about people (sometimes, themselves) to other people, Widdershoven and Smits remind us that stories are means, not ends, through which human relationships and intentions manifest with their myriad ethical dimensions.

In The Wounded Storyteller, Arthur Frank draws from the work of Arthur and Joan Kleinman, whose anthropological analyses of the intricate and mutual relationship between bodies and their cultures over different historical periods led them to propose that, "[a] medical anthropology unable or unwilling to examine how culture infolds into the body (and, reciprocally, how bodily processes outfold into social space) is not very likely to get far in conceptualization and empirical study of the sociopolitical roots of illness or the cultural sources of healing" (Kleinman and Kleinman in Frank, Wounded 27-28). "Bodily symptoms," Frank explicates, "are the infolding of cultural traumas into the body. As these bodies continue to live and to create history, these symptoms outfold into the social space of that history" (Wounded 28). Developing this idea further, Frank suggests that, through stories, "bodily processes outfold" as "culture infolds into the body" (28).

Dissatisfied with anthropological and sociological discourses that described bodies in static and objectified terms, the Kleinmans sought a way to express lived bodies and their intricate and complex connection to historical and cultural contexts. To represent the mutuality of bodies and culture—that is, the outfolding of bodies and infolding of culture—and to emphasize the corporeality of cultural phenomena, the Kleinmans created the term "body-selves" to describe embodied lives (Frank, Wounded 28-29, 32). Drawing from the concept of body-selves, Frank identifies what he calls the four "problems of embodiment" that people must address generally and, in a more self-conscious manner, during illness: control, body-relatedness, other-relatedness, and desire (29).

Whether suddenly or over an extended period of time, the onset of illness precipitates a loss or diminishment of bodily function and/or movement, which may cause discomfort and/or pain. When people become ill, they must evaluate and address their bodily functions and symptoms, which can alter their relationship with their bodies, and, consequently, their relationships through their bodies. Frank proposes that complex cultural and historical processes of infolding and outfolding lie within these embodied relationships during illness. To illustrate the possibilities, Frank considers the four problems of embodiment in terms of four continua of responses to them: control (from predictable to contingent), body-relatedness (from associated to dissociated), other-relatedness (from dyadic to monadic), and desire (from productive to lacking) (Wounded 30). According to Frank, the ideal (in the abstract sense) and idealized (in the ethical sense) state of embodiment for giving witness to illness—what he calls the "communicative body"—would be one where the ill person accepts the contingency of bodily control, feels associated with or is attuned to her or his body, openly relates with

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others in a dyadic space, and actively seeks to address and satisfy desires.[52] However, Frank acknowledges, no one should be expected to attain this idealized ideal, nor should the various permutations of addressing the problems of embodiment be "mutually exclusive or exhaustive" (51). Instead, individuals may inhabit a combination of these states of embodiment over time, while living with or without illness. By establishing an ethical ideal for embodied witnessing, Frank explicates the elements that can hinder the processes of giving testimony to illness.

Furthermore, Frank proposes that different bodies, or states of embodiment, have "elective affinities" to different types of illness narratives, which Frank divides into three categories: restitution, chaos, and quest (Wounded 52). For example, an ill person who embodies what Frank calls a "disciplined body"—that is, whose main preoccupation is to exert bodily control and thus dissociate from her or his body's vulnerabilities—will most likely tell a story of restitution, detailing her or his attempts at regaining a "pre-illness" body. Thus, the story told relates directly to how the embodied narrator addresses her or his problems of embodiment. While Frank does not advocate a rigid ascription or mapping of embodied attributes directly to a narrative structure or form, he does emphasize that the

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[52] Presumably, Frank's four continua of responses to the four problems of embodiment could also be used to describe non-ill bodies (Wounded). Given the bodily difficulties during illness, it could be presumed that a non-ill body would more easily approximate Frank's ideal of the communicative body. In other words, fewer problems of embodiment would allow better responses and facilitate a more communicative body. However, I interpret the problems of embodiment not as hindrances to the communicative body, but as influential means through which the ideal communicative body may be realized or denied. Different problems engender different responses. The problem of not realizing one's bodily contingency—common for many non-ill persons—may work against communicativeness. Thus, being healthy or not ill does not necessarily bring one closer to being a communicative body.

manner in which one addresses the problems of embodiment influences the story one tells and, thus, the person one becomes in that telling.

The existence of an idealized communicative body, however, poses several problems. First, it may be misused to absolve people from the responsibility of listening to stories from "less communicative" ill bodies. If an ill person is struggling to maintain bodily control and feels dissociated from her or his body, the story she or he tells may be more easily dismissed and rejected by listeners (Frank, Wounded 41-42). Conversely, one's closer proximity to the communicative body may be used to commandeer listeners. For example, if an ill person accepts his or her bodily contingency and maintains relationships with others (dyadic), but lashes out at them or attempts to control them (47-48), his or her story may be received with greater consideration, due to the forcefulness of its telling. Yet, such forcefulness can backfire and then, no matter how closely aligned one is to the ideals of the communicative body, one's story may be denied. Hence, the ill person's proximity to the four ideal components of the "communicative body" should not be misconstrued as a way to ascertain or predict which ill people and narratives deserve more or less attention.

During one of my visits, my parents and I went out to dinner to celebrate my father's birthday. At one point, my father and I started laughing about an incident. Tired and barely able to eat, my mother suddenly became enraged and hissed, "Ill people should get whatever they want."[53] Unlike my father and me, she could no longer savour the foods

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[53] Should ill people get whatever they want? Desire is one of the four continua that make up Frank's communicative body. His conceptualization of desire is based on Jacques Lacan's psychoanalytic theory, where desire co-exists in a triad with need and demand (Wounded 37-38). Need, Frank elaborates, exists

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she loved. While my mother's expressive anger demanded an audience, I refused to listen. We fell into an uncomfortable and familiar silence—one that my mother's temper, even before illness, often elicited. Consistent with what had been our history of interaction, I could not give my mother what she wanted, because what she wanted was beyond what I could give. That night, I could not hear her angry demand beyond the history of her other angry demands: I interpreted her outburst as a variation of her standard accusation that, once again, her family did not want to give her what she wanted. What happens to the teller when the listener won't listen? What happens when there exists a conflicted history of telling and listening between intimates? *Mm ho gum bah-biy*. Don't make a fuss. *Moa bahn faat*. No other way. Each woman with breast cancer responds to the crisis of illness out of a history of who she is and how she has lived her life (Lorde, Cancer 9). My mother's history included her family, included me. Thus, to address the problems of embodiment that constrain a communicative body, one must reckon with one's history and the people within it. If the communicative body is as mutual and communal as Frank suggests, then perhaps the listener must also strive to be a communicative body in her or his listening. Thus, the ideal of the communicative body has within it several layers of actions and interactions.

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at the corporeal level and seeks satisfaction; for example, a baby's need for milk. Demand, on the other hand, is the "expression of the need" and contextualizes the need by "ask[ing] for more than the need it seeks to express" (37). A baby's cry—which could indicate hunger, colic, and/or a wet diaper—is a demand that expresses and enlarges what she or he needs. This enlargement or "quality of more" translates into desire (37). According to Frank, people who are ill can lack desire, since suffering may cause a person to dissociate from his or her bodily needs and symptoms (38-40). At the other end of the continuum, a person may be productive of desire through learning to accept and love the bodily scars, changes, and contingencies that illness exacerbates (see Lorde, Cancer). Although, in the context of that dinner, my mother's need was for food, I believe her demand was for the ability to enjoy food and dining out. Perhaps, her desire was to be able to desire. Perhaps, I could not hear that until now.

The problems of embodiment are problems of action, since "as body-selves, people interpret their bodies and make choices" (Frank, Wounded 32, 160). Telling stories about illness can be ethical acts, wherein ill people choose to address their pain and suffering in order to bear witness for others (35-37, chapter 7). Accordingly, then, one's "body is…perhaps *the* moral problem a person has to address" (40; original emphasis). In addition, telling stories can be a reflexive act in that one can "think with stories" (23, 158), and consequently, act with stories. To think with stories—especially, one's own—enables one to replay and continually evaluate one's illness experiences, and allows one to retell one's story in different contexts so that the "[r]epetition [can serve as] the medium of becoming" (159). Repetition breeds familiarity and facilitates refinement. For ill persons, a familiarity with one's story and different kinds of ill bodies and illness narratives enables one to adjust and shift gears in one's telling and retelling—in effect, to change the course of one's "becoming" with illness (158). In this manner, one can refine one's communicativeness, to strive towards a communicative body through a "recursive process" (163-164).[54] If the communicative body is a recursive process, then the story it tells must also be a part of that recursion; the story itself is in a perpetual state of becoming.

The act of telling stories about illness represents a form of "outfolding," as the storyteller works towards a communicative body. Simultaneously, an "infolding" occurs as

[54] To explain his idea of the communicative body as a recursive process, Frank offers the analogy of faith where: "one must have faith in order to be faithful, and being faithful increases the quality of faith. Like faith, the communicative body is always an incomplete project; recursive processes continuously loop, never conclude" (Wounded 164).

conventional and culturally available narrative strategies and structures are borrowed and employed. If we consider that body-selves compose culture and culture is comprised of other body-selves, then the choices—including telling stories—that body-selves make for themselves affect others. Also, if body-selves elucidate their embodiment through ethical choices during illness, then storytelling or bearing witness to illness can be a means through which ill people relate to others as bodies. The act of narrating one's illness can be a choice to "be a body *for* other bodies" (Frank, Wounded 37; original emphasis). However, such narration or "outfoldings" of body-selves are partly comprised of prior "infoldings" wherein cultural influences, including other body-selves, have infiltrated:

> Narrative ethics takes place in telling and listening. There is no such thing
> as a self-story if that term is taken literally; only self-other-stories. The
> stories we call 'ours' are already bits and pieces we have gathered from
> others' stories, and we exist no less in their 'self'-stories. Ultimately
> narrative ethics is about recognizing how much we as fellow-humans have
> to do with each other. (Frank, Wounded 163)

Thus, problems of embodiment are problems of self-realization and *inter*action: how to become and be with other body-selves, and how to act with a conscious awareness of oneself in relation to, and with, others.

The move from the narrative ethics within storytelling to a social ethic requires that we conceptualize what ill people as a group can offer society. As discussed in chapter two, Frank proposes that "what the ill have to teach society" comes through their experiences of suffering, and thus he calls the social offering of ill folks, "the pedagogy of suffering" (Wounded 145). The pedagogy of suffering entrusts ill people with social roles as teachers of, and commentators on, experiences of illness and the cultural and social

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phenomena surrounding illness, including cultural fears about physical vulnerability, the

allocation of health care resources, and the hierarchy of medical expertise. Hence:

> By conceiving suffering as a pedagogy, agency is restored to ill people; testimony is given equal place alongside professional expertise. The pedagogy of suffering does not replace modernist medicine and supporting theories such as the sick role; rather what is opened is the possibility for shifting between frameworks as required by *responding* to the ill. (Frank, Wounded 145; original emphasis)

Illness narratives, under the rubric of the pedagogy of suffering, present listeners and

tellers with reciprocal responsibilities. Just as ill narrators must "be a body for other

bodies," ill or non-ill listeners must respond to testimonies of illness by being those "other

bodies." Frank's call to people with illness and disability to bear witness to their suffering

includes the reciprocal responsibility of intimates and other witnesses to continue the work

of testimony.

Witnessing begets witnessing. "A witness makes a witness of others.... When

someone receives the testimony of another, that person becomes a witness, and so on"

(Frank, Wounded 142). According to Frank's conceptualization, the ill person rests in the

center of "outward concentric circles" (142). Initially, I visualized this geometric

configuration as consisting of discrete rings, wherein the ill person occupied the center

while their intimates rested in the secondary ring, and the witnesses to these intimates lay

in the tertiary ring, and so on—rings expanding outward as if on a dart board. However, if

a witness makes a witness of others, then the concentric outward movement should

originate at each person who bears witness; in which case, each person must be the center

of his or her own set of outwardly expanding rings. In other words, witnesses inhabit their

own centers of influence and communication. A witness occupies not only dual positions

as recipient and source, but also potentially multiple positions as the recipient and teller of various stories.

For non-ill narrators who write, or who collaborate with intimates to write, about an intimate's illness, storytelling is a means by which we can *be* for others in a visceral manner: by enlisting a shared physical vulnerability to suffering and pain. Intimate witnesses encounter dilemmas and assume responsibilities that may appear similar to, yet asymmetrical from, those of the ill person. Frank reserves the term "caregiver" for those who actively listen and care for the emotional and physical well-being of ill persons (At the Will 48-49). These caregivers are predominantly women whose medical careers often cluster at the lower end of the medical hierarchy, or whose socialization has encouraged them to care for others, often to the detriment of their own lives (78, 106). Consequently, caregivers spend more time with ill persons than do medical doctors and specialists, who wield considerably more power within the medical realm, and thus influence the direction of an ill person's treatment. Yet, their observations are often overlooked and dismissed by medical experts, and, I would argue, occasionally by ill persons as well.[55] Nonetheless, Frank affirms their value in a person's experience of illness. Intimate witnesses (living without or with illness) can and should give witness to illness: "Caregivers are the other

[55] In many respects, an intimate witness exists in a compromised position. Because intimate witnesses often hold socially disempowered positions within the medical system (as women and as the system's underlings or as folks without medical education), their professional and personal opinions can be easily dismissed by medical specialists and by ill persons. In addition, an intimate's relationship to the ill person can compromise her or his position. For example, an adult child's opinion can pale before a medical expert's opinion if her or his parent, as the ill person, has never accorded much respect to that child's knowledge. While Frank lauds caregivers, he is not without insight into the burdens that they must bear. In At the Will of the Body, Frank realized that his wife, Cathie, whose mother died from cancer during Frank's treatment for prostate cancer, was afforded little time to mourn her mother in her role as his caregiver (39-40).

halves of the conversations I encourage the ill to engage in. They are also the other halves of illness experiences" (5-6).

As my mother's primary caregiver, my father was the other half of my mother's illness experience. However, my father's limited comprehension of the English language (even more limited than my mother's), combined with his lack of formal education, did not facilitate his storytelling in Canada. Although I was not my mother's primary caregiver, I was privy to my parents' conversations and interactions during my mother's illness. As one of the intimate recipients of my mother's witnessing of her breast cancer, I am now the source of an experiential narrative bearing witness to my mother's illness. People who read my narrative will become a part of my and, to a lesser degree, my mother's concentric worlds or levels of witnessing. My personal becomes her personal, becomes his personal, and so on. Yet, I am also the recipient and reader of illness narratives by Audre Lorde (Cancer), Arthur Frank (At the Will), and Barbara Rosenblum and Sandra Butler.

As a witness to my mother's experiences of illness, her reflections and suffering have infolded into my embodied reality so that my outfolding narrative is infused with memories of my mother; in turn, these memories are framed by illness narratives I have read. The way I am in the world, the way I can *be* for others, is related to the way my mother and I had *been* together. Illness narratives, as a specific form of autobiography or biography, delve explicitly into embodied ways of telling about, and hence being with, oneself and others. As a daughter narrating her mother's illness experience, I choose to be a body for my mother's past body and my father's body, and I choose to be a body for other bodies (e.g. readers and friends). The story I tell about my mother's experiences of breast cancer opens dialogical channels for reflection on her life and the lives of other

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Asian working-class immigrants during illness. By being a body for my mother's past body, I am continuing my mother's work of becoming a communicative body—a process that ended with her death. Where her body ended, mine begins. Where her life ended, my story of her unfolds again and again.

A week later, I said to a friend: I don't
think I could ever write about it.
Maybe in a year I could write something.
There is something in me maybe someday
to be written; now it is folded, and folded,
and folded, like a note in school.
                                    — Sharon Olds[56]

My mother,
alive in the machine,
becalmed on hard white sheets,
the narrative of legs, arms,
animal centers stilled,
some starlight in the mind glittering off
and on, couldn't tell me
whether or not to leave her.
                                    — Stanley Plumly[57]

It has been over two years since my mother's death. Unfolding this narrative has

taken longer than I'd anticipated. The something that was within me has been told. I have

written it out. But it is still unfolding. In this unfolding, I access and refine memories of

interactions, events, and emotions. As an intimate witness of my mother's illness, I sat by

her and told myself to remember. Through my telling, I am becoming a communicative

body for her past body. Despite the differences between us, I feel bound to the memory of

my mother's body as if she formed a divining rod that would lead me to the wet truth of

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[56] Sharon Olds, "A Week Later," The Atlantic Monthly July/August 2002. 146.

[57] Stanley Plumly, "Mercy," The Atlantic Monthly September 2002. 103.

my body. My narrative about my mother's breast cancer is my response to her death and my continuing life.

By responding to ill people, we accept the reciprocal responsibility to which their embodied testimonies challenge us: to be the body for which an ill person is being a body. To be a body for other bodies, however, puts us in a compromised position: a) as a body for other bodies, we admit an appreciation of our physical vulnerability and mortality— that we can be hurt by other bodies, or by our own failing physiology; and, b) as a body for other bodies, we acknowledge how much we have to do with each other in our embodiment—how much we need other bodies to sustain our own with nurture and love. When we act as a body for other bodies (by telling illness stories) or as reciprocal bodies (by listening to illness stories), we affirm a phenomenon of embodied interdependence and susceptibility that clashes with cultural ideals of independence and individualism.

Within illness narratives, embodied interdependence is represented by what Arthur Frank describes as "dialogical engagement," whereby a destabilized narrative consciousness relinquishes its authority so that the distinction between the narrator and reader dissolves into a cacophonous and polyphonic interaction ("Illness" 7-10, 22). What distinguishes illness narratives from other experiential narratives is the stark embodied vulnerability, and thus potential narrative instability, of the narrator. Will she or he be able to finish the story? When will illness overwhelm narrative ability and energy? In this respect, illness narratives convey a rich sense of narrative instability and dialogical need in the actual narration, and not only in the reception, of the story. Readers expect other voices to appear as narrative guides in illness narratives. They expect medical opinions from doctors and nurses. They anticipate surviving loved ones to complete the story, to

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detail the ultimate ending: the narrator's death. Some narrators include the perspectives of loved ones and caregivers, especially during periods of relapse and physical and/or psychological infirmity (see, for example, Klein). Illness narratives, because of the potential incapacitation of the narrator, rely on more than a single, unitary consciousness to direct and maintain the narrative flow.

The narrator's destabilized consciousness—due to the effects of illness and the isolation within medical realms and narratives—and its consequent cultivation of dialogical space are what distinguish illness narratives from other experiential narratives. They are also what lend illness narratives sociological value, for they allow ill narrators embodied communication with and beyond themselves (Frank, "Illness" 31-32). A destabilized narrative consciousness allows readers to read beyond narrative construction and authority to perceive, as it were, the narrator in the process of self-discovery, or caught off-guard by a course of events or by interactions with other consciousnesses (30). Also, a destabilized narrative consciousness is porous—open and vulnerable to other consciousnesses in the act of storytelling. Hence, the power of self-representation within illness narratives is more overtly (read: physically or physiologically) compromised, and its compromised position appears more transparent to readers. This compromised narrative serves to destabilize the reader's consciousness: the reader cannot read passively, expecting to be told narrative truths; instead, he or she must work to sift through and discern the various consciousnesses. Thus, Frank concludes, "autobiographical work is not a spectator study but a relation" (22). An illness narrative's dialogical potential lies in its narrative openness and vulnerability. What makes an illness narrative is what unmakes it.

The destabilized reader may respond with what Ross Chambers calls "anxious reading." In his analysis of AIDS diaries, Chambers has observed that these diaries often served as position papers and wills (similar in tone to Barbara Rosenblum's ethical will) whose textual survivorship contrasts starkly with its author's death (95-98). Knowing this, attentive readers can only anxiously read AIDS diaries:

> Anxiety is what arises, for a scrupulous reader, from the fact of being separated from direct textual access by the author's death, which itself grounds the act of reading, whether that phrase be understood in a theoretical or an actual sense, so that the double bind the distance of reading enforces is similar in its effect to the double bind inflicted on the friends and caregivers of a difficult patient: the more they try, the less they succeed. (Chambers 112)

AIDS diaries, like difficult AIDS patients who won't let friends get away with being complacent witnesses, confront readers with the injustice of homophobic discrimination and the guilt of survival (98-99). As a reader who has survived the author's death, what will you do about the author's account of his or her suffering? Anxious reading, then, solicits an embodied response by confronting the reader with his or her physical survivorship.[58] "You," the AIDS diarist seems to accuse, "are alive and I am not." To be a

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[58] In Facing It: AIDS diaries and the death of the author, Ross Chambers argues against the possibility of readerly engagement and concern with respect to AIDS diaries, which confront readers with the author's death and the reader's survival (113). According to Chambers, the AIDS diarist's death grounds the possibility of the text; however, the diarist/author's death simultaneously disempowers the text by exposing the author's absence during its reading (111-113). Yet, the act of reading empowers the text and makes possible a "textual afterlife" that survives the writer (viii). The textual afterlife, dependent on the survivor's reading and made possible by the author's death, puts the surviving reader in an odd position: to confer power upon the text requires acknowledging the author's disempowerment (in death), which ultimately compromises the power of the text (viii). As a result of this contradiction, the reader can't engage with the text. Instead, the reader's possible relationship with the text oscillates between complacency and anxiety, where, at best, the readers and writers can only engage in a shared project of witnessing that requires "facing" the lived and representational limits and contradictions inherent in writing and reading about living with AIDS and in being a survivor who bears witness to those who have lived with and died from AIDS.

body for other bodies, then, involves acknowledging that we are indisputably alive with all that that entails—being socially responsible, struggling for political rights, and admitting susceptibility to illness and death. Furthermore, to be a body for bodies—especially ill, dying or dead ones—entails that we, as intimate witnesses, delve into our own embodied histories and memories, to become our own communicative bodies and tell our own stories.

According to feminist psychoanalysts, our past and memories are not straight-forwardly accessible (James; Meyers). When we tell about our past, we include stories we continually learn through culturally available narratives, such as those about social expectations of immigrants, Asians, mothers and daughters. Also, each time we narrate, our memories change, since we may highlight different points or include the changing memories of others. Autobiographical memory, then, may be malleable and replete with cultural figurations. Diana Tietjens Meyers contends that autobiographical memory: a) represents not only subjective (i.e. literary) but also intersubjective elements, since one's memories change over time and through others' recollections of the same events, and; b) imports and relies upon cultural figurations (i.e. metaphors, symbols, etcetera) in its narrative task (236, 239). In autobiographical memory, cultural figurations hold enormous influence over one's sense of narrative accuracy. For example, cultural figurations such as Sigmund Freud's psychoanalytic theory of the Oedipus and Electra complexes—that link female and male psychosexual development with incestuous fantasies—can lend credence to the diagnosis of "false memory syndrome," which claims that people's, primarily women's, memories of incest and childhood sexual abuse "recovered" through psychoanalysis are false and attributable to the power of suggestion of therapists (238-

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240). Meyers argues for a conscious appreciation of these stock cultural symbols and their influences on our self-knowledge and memories (242).

Illness stories reveal prevalent cultural figurations available to ill persons and their loved ones as they attempt to narrate and organize their illness experiences (Hawkins 3-5). Barbara Rosenblum discerned the ways in which her illness experiences, including misdiagnoses by medical experts, were related to her location as a woman from a working-class Jewish background (23-27). Illness made her vulnerable to cultural histories and stories that constructed her comprehension of herself as a composite of various identities. While undergoing medical treatments, Rosenblum wondered if her embodied experiences resembled those of her relatives who suffered under the Nazis' cruel medical experimentation (49). Conversely, Rosenblum's embodied histories and identities may have left her vulnerable to illness.[59] As previously discussed in chapter three, working-class immigrants often accept health care "as-is," instead of questioning its appropriateness, validity, and accuracy, because of language barriers, limited educational opportunities, and the dynamics of class, race, and gender biases. Did Rosenblum's working-class Jewish immigrant expectations of health care, Rosenblum and Butler separately wondered, make her more vulnerable to misdiagnosis?

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[59] In her book, No Longer Patient: Feminist Ethics and Health Care, Susan Sherwin makes an important connection between illness and oppression. Working from the premise that North American society is generally racist, sexist, classist, heterosexist, and ableist, Sherwin argues that those who are oppressed and socially marginalized "will experience a disproportional share of illness and will often suffer reduced access to resources. Moreover, the connection between illness and oppression can run in both directions; because serious or chronic illness is often met with fear and hostility, it may also precipitate an individual's or family's slide into poverty and therefore lead to oppression based on class" (223). Also, Zillah Eisenstein points out that poorer people—predominantly, people of colour—tend to work and live in environments that contain carcinogenic pollutants and chemicals that are hazardous to their health.

How illness makes us socially vulnerable and how social vulnerability may predispose us to illnesses are concerns that intimate witnesses of people living with illness must address, since their life histories and identities are often intertwined with those of the ill person. Intimate witnesses have vested interests in illness narratives, especially those that can make or unmake their own life stories. Moreover, the experiences of people with illnesses may foretell their intimates' illness experiences, not only through genetic lineage, but also through cultural and social proximity. Perhaps that is why we often accept the word of intimates as the word of the sick one or the survivor—narrative proxy by personal proximity (Hawkins 3). When non-ill persons are intimate with people living with illness, stories about illness become enmeshed within non-ill persons' experiential realities. My story about my mother's illness has as much to do with my past as with my future. I retrieve and reconstruct us from my memories.

Despite the intersubjectivity and cultural interpolation of memories, Meyers notes that people often recall and represent past experiences with certainty, because memories often form the basis of personal identity. "The continuity of one's memory sequence sustains one's sense of ongoing individual existence," Meyers maintains, "and one interprets one's experience and choices and ascribes meaning to one's life in part by invoking memories" (236). By articulating the past, we can construct memories that allow us to anchor our personal identities through "figurative self-definition" (241-45). Using available narratives, we can define and identify ourselves.

Available narratives, however, can work against our attempt to define and figure our identities. Cultural figurations, such as what Meyers calls Freud's "family romance" involving the Oedipus and Electra complexes, can put into question a person's memories,

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causing her or his credibility and identity to come under attack. To counter these self-effacing and self-diminishing effects, we must avoid mistaking cultural figurations for literal truths, counter harmful figurations, and expand the repertoire of culturally available figurations (243, 246). To do this, Meyers suggests that we engage in the "counterfiguration project" that African-Americans, Latinos and lesbians have already started in their reclamation and reconception of their identities.[60] Meyers draws on the work of Maria Lugones, who maintains that she can be a different person in different cultural contexts: in effect, "a multiplicitous self" (248). Hence, when we access our memories to narrate our lives, we must acknowledge the multiple locations that can constitute the self and challenge stock cultural figurations by counterfiguring as we go. In other words, during our outfolding, we must interrogate what we have infolded. Often, stock cultural figurations that we have infolded, such as "ill persons as needy pariahs" or "Asians as evolutionary throwbacks," may hinder and/or corrupt our telling. Counter-figuring, then, can be a project of unfolding what we have infolded.

In order to counter-figure as we tell our stories, we must take stock of stories that contain common cultural figurations. Discursive space is crucial as a site of epistemic validation, because we learn about ourselves and each other through available stories—

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[60] In Borderlands: the new mestiza = La frontera, Gloria Anzaldúa examines her contradictory locations as a lesbian, a Latina, and a feminist academic. Rather than divide herself up along her various identities, Anzaldúa decides to embrace her marginality within different identity categories and make that marginality, which she calls the "borderlands," the new frontier of identity construction. In her essay, "The Names We Give Ourselves," Martha Gever states that there is no such thing as a unified and coherent lesbian community. She reflects: "I find every effort to define a "lesbian sensibility" or a "lesbian community" untenable.... My experience has taught me a few things. Above all, it has taught me that to be a lesbian means engaging in a complex, often treacherous, system of cultural identities, representations and institutions, and a history of sexual regulation" (191). To be a lesbian, one must shift among various locations and identities.

usually, culturally dominant stories or what academics or cultural critics refer to as "master narratives" (Nelson). Hilde Lindemann Nelson contends that these master narratives distort the realities of marginalized folks through various means, including the reinforcement of their social absence and the proliferation of stereotypes that exaggerate socially negative, and/or diminish positive, characteristics. Such misrepresentation affects how marginalized folks regard themselves and how others regard them. Our perception of—or how we identify—a group or members of a group influences our attitudes towards them and, ultimately, how we treat them (Nelson xi-xii, chapter 1). In addition, master narratives hold sway over members of marginalized groups who believe the biased stories about themselves; their self-perception and self-identification may thus be compromised.

For my mother, her resistance to and acceptance of her location as a working-class, Asian immigrant woman living with breast cancer echoed through her phrases of *mm ho gum bah-biy* and *moa bahn faat*. As previously discussed in chapter three, working-class immigrants have been, and continue to be, portrayed as hardy, resilient and stoic—tolerating and overcoming the hardships in Canada in order to make a better life. While some immigrants rejected this master narrative at the outset, other immigrants—including my parents, as I perceive them—navigated along the outlines of socially dominant expectations. As children of immigrants become linguistically and culturally fluent in Canada, however, their propensity to speak out and assert their presence may cause their parents a measure of discomfort. When I approached doctors and nurses to gather information about my mother's treatment, my mother seemed uncomfortable—perhaps with my seeming brashness and aggressiveness—and chided me with *mm ho gum bah-biy*. After all, I was only the daughter of a working-class Asian immigrant woman. Yet,

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sometimes, my mother seemed to appreciate my dogged attempts to gather medical information from health care workers. One time, she leaned towards me and said in a conspiratorial tone that was tinged with pride, "Your brother doesn't ask as many questions as you do."

Growing up in Canada and observing my parents move within Canadian society, I have learned the master narratives that construct, enable, and simultaneously damage our identities within this country. Master narratives about Asian immigrants as silently resilient and stoic, and about Asian immigrant women as self-sacrificing and compliant, infuse the expectations my parents had of their lives and mine. As the daughter of Asian working-class immigrants, I was raised to know "my place" and "stay in place" within the home and within society. In writing about my mother's illness, I comprehend more clearly how my mother might have seen me as her daughter. In many respects, we became strangers to each other, in part because of the different ways we addressed the master narratives that shaped our lives. As a mother, she had been responsible for raising her daughter to be aware of the cultural constraints (supported by master narratives) encountered by Asian women in Canada. In her responsibilities to me, I saw only that she wanted to control me, not that she had limited access to counter-narratives with which to help me realize my life. In turn, I had accepted the racist and sexist stereotypes that constructed my mother as a culturally backward and typically "hysterical" woman who could not understand my progressive Chinese Canadian life.

Through insidious stereotypes and denial or dismissal of self-representational efforts, master narratives distort the identities of marginalized folks and influence both how others treat them and how they treat themselves (Nelson chapters 3 and 4). I imagine

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that my mother's compliance with medical advice and her reluctance to speak out in the strangeness of medical encounters combined with her sense of physical vulnerability to allow health care workers to treat her in a different manner than if she were medically knowledgeable and/or non-compliant. Switching roles from daughter to health care worker, I wonder if I feel less accountable to those who appear less medically savvy and ask me fewer questions. Do they register less on my pharmacist radar? Is it my responsibility to include them despite their silence and compliance? When I speak to people about their medications, I sometimes see my mother in their gestures, their silent nods and lack of questions. In a busy health-care environment such as the retail pharmacy in which I work, it would be so easy for me to walk quickly away without ensuring that they have an opportunity to understand what their medications could mean to their experiences of illness. Sometimes, I stay and wait, attempt to act unhurried. Other times, I rush unthinkingly away. Master narratives are powerful because they have infiltrated our lives so completely that no effort is required in our acceptance of their interpretations. "Poor, homeless, and/or uneducated people don't know how to take care of their health." "Immigrants and refugees don't understand how the health care system works." "Old people are senile and can't comprehend medical information." As a health care worker, it is easier to discount people than not. Hence, within abusive systems of power, master narratives pose moral harms by facilitating the mistreatment of marginalized folks through the dismissal or downplaying of society's ethical obligations and social accountability to them. Stories about marginalized groups authored by their own members, therefore, possess the potential not only to claim discursive space, but also to ameliorate moral

harms, provided that they resist and challenge the misrepresentations of master narratives (Nelson xii, chapters 1 and 5).

For people living with illness and disability, their stories are told against a backdrop of medical myths, other illness stories, and master narratives about illness and disability.[61] Their stories may include embedded cultural myths and expectations about illness, including the role of personality and attitude in healing, the ill person's responsibility for the onset and continuation of illness and for healing, the promise of biomedicine and medical technology in divining a cure, and the caring roles of friends and family members. Their stories may counter and challenge the depersonalized scientific and medical master narratives about disease and disability by pointing out social injustices and providing details of and reflections on suffering.[62] "Counterstories," Nelson explains, are narratives that intentionally or unintentionally debunk harmful stereotypes and cultural metaphors; thus, they serve to remedy the morally and psychologically diminishing effects of master narratives (6-9).

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[61] Breast cancer activist and feminist Zillah Eisenstein contends that master narratives about cancer are constructed by the forces of a "postindustrial-medical complex" (68-69, 88). Popular knowledge about cancer, specifically breast cancer, is transmitted through the discourses of scientific and medical establishments that are, in turn, intimately connected to pharmaceutical and chemical companies within the international industrial complex (68-70). Eisenstein astutely questions the links between the problem and solution of cancer: companies that manufacture chemotherapy drugs also manufacture pesticides and other carcinogenic substances.

[62] People living with illness and disability, disability activists, AIDS and cancer activists, feminists, and medical sociologists make a distinction between illness and disease. The word "disease" denotes a medical description and classification of a physiological condition or disorder whose symptomatology dictates its diagnosis and subsequent treatment. In contrast, the term "illness" is used to resist the depersonalization of medical description; instead, it prioritizes the experiential aspects of physiological conditions and physical suffering (see Arthur Kleinman's, The Illness Narratives).

To succeed as a counterstory, then, an illness story must not add to the suffering already experienced by people living with illness. Additionally, an illness counterstory should serve to ameliorate suffering or provide support. According to Nelson, stories can benefit marginalized people or "do good" by challenging their harmful characterizations in master narratives. Ideally, all illness stories should be good counterstories. But what makes a good counterstory? Among other criteria, Nelson proposes that good counterstories should constitute identities, resist master narratives constructed within an abusive system, and attempt to repair the damage of these master narratives (156-57). In short, counterstories enable us to repair our identities while we constitute them. Good counterstories should not fall prey to over-generalized claims, the reinforcement of one master narrative in an attempt to depose another, or the positive portrayal of an individual at the expense of others in his or her group(s) (176-183).

Meyers's "counterfiguration project" is made explicit through Nelson's definition of counterstories and her description of their potential uses. When we tell stories about ourselves, we must evaluate how our memories are saturated with cultural figurations that affect our telling. If telling stories, especially illness stories, about ourselves requires us to engage in the recursive project of striving to be an ideal communicative body—that is, a "body for other bodies"—and if the communicative body infolds and outfolds in its ongoing struggle with the problems of embodiment, then the acts of "counterfiguring" and "counter-storytelling" must approximate a process of unfolding tight and complex knots of master narratives that constrain and limit our narrative and our becoming. By untying or loosening these figurative knots, our stories can outfold in a less restricted manner, and, thus, our bodies can be bodies for other bodies with more freedom. For example, by

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challenging and countering the stigmatization of a one-breasted woman with breast cancer, Audre Lorde took pride in her scarred body (Cancer). In turn, her bodily pride and acceptance facilitated her positive association with her body and other scarred and ill bodies within her illness narrative, which elicited powerful responses from both ill and non-ill people.

Within and through illness narratives, the reciprocal responsibilities of embodied witnesses and their intimate witnesses include working to repair identities (Nelson) and facilitate community building (Frank, "Illness") among those living with illness and disability. For ill persons and their intimate witnesses, what they "have to do with each other" is made stark through their embodied witnessing and their narratives of arms and legs that hold us and won't let go. As a daughter narrating her mother's illness with breast cancer, I came to realize how much my body has to do with other bodies, especially my mother's past body, in my political endeavours and identities. Writing down my mother's past body, I note the outlines of my own body. Explicating my mother's identity as a working-class Asian woman, I see our identities refract and reflect off others. After so many years of rebelling against my mother and her values, I am surprised to find myself very much my mother's daughter. Her illness and death brought to the fore how much her body had to do with the existence of mine.

Poet Betsy Warland poignantly observed, "I became aware of a primitive notion at work within me: / if my mother dies, I die" (98). Yet, Warland continued:

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As close as we became, her death was her own.

Mine will be mine.

What I know is that it has been an almost consuming
internal wrestling match. Like a birthing. Into mother-
lessness. (98)

Although my mother's body had much to do with mine, my body and life are my own, as

my death will be. Being the daughter of a working-class Asian immigrant woman, I

possess different responsibilities to my past and present than my mother. In writing about

my mother's experiences of illness and dying, I have assumed the responsibility of

narrating our lives. According to Shari Stone-Mediatore's interpretation of Chandra

Mohanty's work (as discussed in chapter one), narratives of marginalized experiences that

historicize experience can cultivate a community consciousness that can serve as an

"oppositional consciousness," enabling us to discern the contradictions within our lives

(123, 125). The ways in which my mother perceived her illness and medical treatments,

and the manner in which I responded to her, reveal our shared understanding of our

identities and roles within Canada, and our responsibilities to each other as mother and

daughter. My birthing into motherlessness released me from my historically conflicted

relationship with my mother, and allowed me to claim my own life, body and mortality. To

historicize experiences, then, is to allow cultural and political histories to claim you even

as you consciously oppose them. In death, my mother finally claimed me as hers. Her

embodied testimony of her life and illness pushed me to remember and narrate from my

location as a daughter with academic opportunities.

To cultivate an oppositional consciousness, I situate my narrative of my mother's

illness in the oppositional genre of counterstories. Through writing about her experiences,

I realize the harms that master narratives had inflicted upon her life before and with breast cancer, and upon our on-going relationship. In conversations with people whose parents have died, I learn about my responsibility and relationship to the dead—that we are responsible for their memories, and that we continue to relate to them in our lives and in their deaths.[63] In this regard, narratives of illness by intimates, such as daughters, spouses, and friends, may serve not only to repair our identities, as Hilde Lindemann Nelson asserts, but also to repair our memories and our pasts. How we remember people—for example, the significance we make of their lives as we recall them—can serve to enlighten the feminist and critical pedagogical project of constantly retrieving and remaking our past and present in order to counter oppressive forces and disempowering dominant narratives. Arthur Frank's (Wounded) proposal that ill persons are responsible for bearing witness to their illnesses finds its significant parallel in the witness's responsibility to remember and retell. As I prepare to step away from this page, I find myself disassembled and retold through my mother's ill body and my unfolding memories of her. What began as a narrative about my mother's illness and death opens into a narrative of my own arms and legs. To borrow from two poets, Lorna Crozier and Audre Lorde (Marvelous), our dead and ill behind us are what the living won't let go. This is the business of being bodies for other bodies.

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[63] In separate conversations with Susan Wendell, Rizwana Jiwa, Mona Oikawa, and Susanda Yee.

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