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A quest through chaos: My narrative of illness and recovery

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About

Gender forum is an online, peer reviewed academic journal dedicated to the discussion of gender issues. As an electronic journal, *gender forum* offers a free-of-charge platform for the discussion of gender-related topics in the fields of literary and cultural production, media and the arts as well as politics, the natural sciences, medicine, the law, religion and philosophy. Inaugurated by Prof. Dr. Beate Neumeier in 2002, the quarterly issues of the journal have focused on a multitude of questions from different theoretical perspectives of feminist criticism, queer theory, and masculinity studies. *gender forum* also includes reviews and occasionally interviews, fictional pieces and poetry with a gender studies angle.

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Editorial

By Carmen Birkle, Philipps University, Marburg, Germany

1 This thematic issue of *gender forum* is part II of a collection of essays focusing on the intersections of medicine, literature, and gender. In contrast to the first issue with its contributions on the representation of women in the medical profession from historical and literary points of view, in this second part personal narratives take center stage. Here, all contributions emphasize the healing power of grief and illness narratives in their various sub-genres, such as written testimonies, diaries, blogs, and artists' books, thus in a multiplicity of autobiographical or auto-ethnographical writings. Some of the authors interweave theoretical discussions or analyses of other people's narratives and their own illness narratives. In doing so, they all demonstrate that they share a belief in the illness narrative as a new space of communication between readers and artists and, ultimately, doctors and patients.

2 More than part I, part II foregrounds the structures and functions of narrative for both writers and readers. Translating personal experiences—which have shattered the “reliance on the orderly functioning of [people's] books” (Becker 12)—into narrative—and thus overcoming “the resistance of a collapsing body to verbalization” (Rimmon-Kenan 245)—gives voice to its author and structure and coherence to often traumatic events in someone's life. Such a narrative also reaches out to its readers and establishes a community or continuum between author and reader. The healing powers of narrative, which allow the patients to regain (at least partial) control over their bodies, is complemented by the insights doctors can gain: “[...] through the study of narrative, the physician can better understand patients' stories of sickness and his or her own personal stake in medical practice [...]” (Charon et al. 599).

3 **Bärbel Höttges**'s contribution on blogging the pain not only is a discussion of the most recent form of grief narrative, namely blogs, but also lays the theoretical foundation for a distinction between more traditional grief narratives told from hindsight and the immediacy of blogging. As Höttges finds, the more traditional form allows for a narrativization of the events, i.e., the author attempts to make sense of the past through the narrative, to give order and coherence to the experiences, and thus to come to terms with the events. In these narrativizations, the healing power of narrative as well as the successful formation of a new identity after the experiences of pain, suffering, and death (of a loved one) can unfold. In contrast, blogging as a form of emplotment tries to shape the future since the outcome of the events is open-ended. Thus, blogs do not convey a sense of order, coherence or closure. As Höttges shows, the mode of publication strongly influences the writing process.

4 **Katie Ellis**'s article equally embraces the healing power of illness narratives and intertwines a theoretical discussion of these narratives with her own illness narrative since she suffered from a stroke when she was only 18 years old. For Ellis, this stroke has changed her life, and over the years she has attempted to make sense out of these changes. Writing as a critical disability theorist, Ellis uses Arthur Frank's narrative structures and uses his three categories of chaos, restitution, and quest narratives. A lack of reflection and understanding in the first type of narrative is replaced by the desire for a restoration of health in the second, and finally by a critical reflection on a changing identity in a culture of health in the third type of narrative. Joseph Campbell's concept of the hero's journey helps her to read this narrative development as constituted by a departure from a familiar life (first stage), a process of initiation into illness and suffering (second stage), and, finally, a moment of return as a changed person with new perspectives (third stage).

5 **Elizabeth J. Donaldson**'s essay demonstrates how illness writing and autobiographical or life writing intersect. She shows how Lauren Slater, a psychologist and patient herself, plays with the genre of memoir and the contract of writing truthfully which writers of a memoir are expected to have with their readers. In contrast to her *Prozac Diary* (1998)—Slater's auto-pathography, which documents her life with major depression and her cure with the drug Prozac—*Lying* (2001) is "a metaphorical memoir," as Slater herself terms it. Here, the lines between fact and fiction are thin, and readers perceive a parody of the illness narrative highly critically. As Elizabeth Donaldson suggests, *Lying* is a "complex hysterical conversion" which describes epilepsy as engendered by Slater's mother. It is the mother figure whom the daughter makes responsible for her epileptic seizures. In this sense, this epilepsy is "a real metaphorical illness." Playing with the genre conventions of both medical and memoir discourses, Slater's memoir, as Donaldson finally argues, resists the pathologization and categorization that societies impose on their members with the latter's complicity in this process. Slater's "life writing" also questions how strongly psychiatric diagnoses and the reading of an autobiography / memoir depend upon narratives and their pre-given categories and conventions. It is thus that a sane person can easily be pronounced insane and vice versa. But Slater, as disability studies scholars warn, also undermines the necessary credibility of illness narratives and their potential healing powers.

6 In contrast to Slater's deliberately staged and faked illness narrative, **Aimee Burke Valeras**'s contribution focuses on the examples of four women with hidden disabilities and their daily decisions of whether to disclose their disabilities or to "pass" for able-bodied, as Valeras explains. Valeras intersects these four case studies with her own example, suffering

herself from Muscular Dystrophy. Here, too, all illness narratives reveal the difficulties and complexities of self-disclosure as well as of the process of identity formation. Mary's Mitochondrial Myopathy, Victoria's Juvenile Rheumatoid Arthritis, Angela's Epilepsy, Rosalina's Celiac Disease, and the author's own Muscular Dystrophy provide ample examples of how concepts of self—both as women and disabled—are affected by everyday performances. Valeras points out how women with unapparent disabilities live with the paradox of fulfilling neither society's expectations of femininity nor the feminist call to resist stereotypical feminization. Disabled women live in-between two worlds—both in the nondisabled world and in the disability world—and have to cope with the expectations of both.

7 **Stella Bolaki's** essay is the first of three essays that deal with women's strategies of dealing with breast cancer. She, too, explains that illness narratives in their various sub-genres are one way of coming to terms with such traumatic experiences. Such narratives, as all contributors suggest, give voice to those who are affected as well as possibly power to effect change, for example, in doctor-patient relationships. With her example, Martha Hall's artists' books, Bolaki demonstrates how Hall hoped for an impact on future physicians and the medical community by inviting her readers as witnesses to her story of illness. Bolaki suggests that since doctors are faced with patients' narratives that need to be interpreted, artists' books could become part of a doctor's training. The advantage of artist's books over other illness narratives is that they return their readers to the body because of their materiality, i.e., the material the artist uses to produce them.

8 In contrast to Martha Hall's artist's books, **Julia Mason** analyzes the representation of breast health in 32 articles selected from a total of 44 American women's magazines consulted. As she argues, many women increasingly use these magazines for information about breast health, and, at the same time, they also publish their personal narratives in order to give voice to their experiences and to inform other women. Mason, too, suggests that these narratives have an empowering function for both their readers and their writers. However, these narratives, since they are written in a specific cultural context, often reinforce narrow social constructions of gender. A greater variety of these personal narratives in magazines, which right now are mostly written by heterosexual white and African American women, would enhance the insight that breast health in general and breast cancer in particular do not just have individual but also social and medical dimensions and, as Mason points out, would ultimately increase the potential for women's empowerment.

9 **Cecile Ann Lawrence**'s discussion of race and breast reduction surgery continues the issue's focus on the intersection of women's health, the body, and constructions of femininity in the context of medical discourses and doctor-patient relationships. Lawrence intersperses her theoretical discussion of what it means to have breast reduction surgery with a third-person narrative in the stream-of-consciousness style, an auto-ethnography, as she terms it, in which she foregrounds the tension for those women who undergo such a treatment. In contrast to the previous contributions, Lawrence thematizes not so much the implications of the illness narrative but rather those of cosmetic surgery and, perhaps also, whether such procedures are, as she terms it, "medically necessary." Furthermore, Lawrence suggests that the "right" size and shape of breasts in / after surgery are determined by the (subjective) male point of view, represented, for example, in the fact that most surgeons are still male, as Lawrence posits. The narrative difference between a theoretical and scholarly discussion and a personal narrative, also reflected in the choice of italics for the latter, lies in the notion of emotional distance. A rather rational analysis is complemented by emotional immediacy—a technique which facilitates the "narrat[ion] of the unnarratable" (Rimmon-Kenan 241) and brings together and effects more humane understanding between doctor and patient.

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Blogging the Pain: Grief in the Time of the Internet

By Bärbel Höttges, Johannes Gutenberg-University of Mainz, Germany

Abstract:

During the last few decades, grief narratives have become increasingly popular. Especially women, who traditionally take over the responsibilities of a caretaker, have used this narrative genre to express and deal with their losses and to share their experience of grief with a larger audience. With the advance of the Internet, grief blogs have started to complement printed grief narratives, offering a virtual version of the traditional genre of grief writing. This article compares these two versions of grief writing. Drawing on narrative theory, the essay reveals that virtual grief narratives do not merely offer a screen version of a printed text. Rather, blogs produce a new form of grief writing, which decisively differs from its printed counterpart despite many thematic similarities. A text, the essay suggests, is thus defined as much by the act of writing, editing, and publishing as by traditional narrative categories such as topic, voice, and perspective. A comparison of printed grief narratives and grief blogs consequently not only documents a reinvention of grief writing on the Internet, but it also reveals a web-based redefinition of (auto)biographical writing in general.

1 On August 31, 2008, a 12-year-old boy named Keeghan died from a brain tumor in Washington, D.C. The boy's death caused a wave of sympathy from hundreds of people all around the world, not because Keeghan had been a public figure in any way, but because his mother, Sharon Barry, had documented Keeghan's fight against cancer in an online diary, a so-called blog, which had attracted more and more readers since its inauguration in 2006. Barry's webpage is just one blog out of many dealing with illness and death. More and more people have started to publish their experiences with cancer and other diseases online, and many of these webpages have gathered a notable number of regular followers. At first glance, virtual grief narratives simply seem to be a variant form of printed grief narratives, which also have become increasingly popular over the last few decades. A closer look reveals, however, that blogs do not only reinvent the genre of the grief narrative but also reflect a web-based redefinition of (auto)biographical writing as such.

Grief and Writing

2 Grief writing is not a new phenomenon. From Anne Bradstreet's autobiographically inspired poetry on the death of her grandchildren to Joan Didion's *The Year of Magical Thinking*, the subject of illness, suffering, and death has been transformed into literature over and over again. The personal encounter with illness, caretaking, and dying, it seems, can be a trigger of literary activity, not because grief is experienced as a creative high, but rather because writing can apparently help the mourner to come to terms with the feelings of loss

and despair. Psychologically, writing fulfills two important functions in the process of mourning. First, it can help to “[keep] the deceased person alive socially and culturally through the narration of his or her life and death” (Klugman 169). The influence of the deceased is not annihilated by his or her death, and the written words preserve his or her life and protect it from dissolution and the destructive forces of obliteration. Secondly, grief narratives contain an educational potential, as they teach both the writer and the reader the wisdom that can be extracted from the experience of caregiving, dying, and grief (cf. Klugman 169). As a result, grief narratives almost always contain lessons about the human condition, and they often insistently uncover and illustrate the factors and forces that really matter in life.

3 The potential of grief narratives to turn mourning into knowledge and a sense of thankfulness is closely connected to the act of writing itself because writing can be a force realigning the writer with the world. This healing capacity of writing becomes evident once the destructive consequences of sickness and death are considered. Fatal diseases constitute a disruption of life, not only for the patients but also for those caring and mourning for them. Pain, both in a physical and a psychological sense, can unhinge the world. Things no longer are the way they used to be, and the natural order of things collapses. In pain, the medical anthropologist Byron Good explains, inner and outer time—*durée* and cosmic time to use Alfred Schutz’s terminology—no longer match: Time caves in. Past and present lose their order. Pain slows personal time, while outer time speeds by and is lost. [...] [T]he world of pain [...] cannot be sustained by language. It is a world threatened by dissolution. Space and time are overwhelmed by pain, and the private world not only loses its relation to the world in which others live, its very organizing dimensions begin to break down. Pain threatens to unmake the world, and in turn to subvert the self. (126; cf. Schutz 214-18) These observations, Good maintains, also apply to those in acute mourning. In grief, the world loses structure and coherence as well, and the mourner experiences a sense of alienation: “For the mourner, the world also appears unfamiliar; people are strange, the landscape unnatural, movement stops midstream. The mourner has an acute awareness of the conventionality of the objects we live among; nature appears alien” (130-31).

4 This breakdown of a mourner’s world—the “lifeworld” or *Lebenswelt* as the philosopher Edmund Husserl calls it (108)—is closely related to a breakdown of the self. The person’s sense of self changes with the death of what the medical anthropologist Craig Klugman calls a “relational anchor” (174-75)—a relative or close friend, whose existence shapes and defines one’s identity, behavior, and self-perception. The death of such a person

forces the mourner “to reassess his or her self-identity” (Klugman 174-75) since existing models of selfhood can no longer be maintained: With the loss of the individual who gave a person that specific relational aspect of identity, the person must rewrite the story of the self. The self that was a parent before the death of a child is no longer a parent in the same way after the child’s death. Thus the person must write a story of a new self as the parent of a deceased child or as a person who has no child. (Klugman 154)

5 Grief writing is a strategy that can help the mourner to overcome both the breakdown of the self and the sense of alienation caused by the death of a relational anchor. This healing potential of grief writing is connected to the restoration of language. Pain, as Elaine Scarry writes in her book *The Body in Pain: The Making and Unmaking of the World*, is not only “world-destroying” (29), it also shatters language (cf. 5): “Whatever pain achieves, it achieves in part through its unsharability, and it ensures this unsharability through its resistance to language” (4). Indeed, “[p]hysical pain does not simply resist language but actively destroys it, bringing about an immediate reversion to a state anterior to language, to the sounds and cries a human being makes before language is learned” (4). These observations also apply to intense and acute psychological pain—grief—which also resists language and articulates itself in cries, screams, and sobs instead. Attempts to “invent linguistics structures that will reach and accommodate this area of experience normally so inaccessible to language” (6), then, can only be made retroactively, once the wave of pain has subsided enough to allow access to language once more. If the attempt to describe the pain of grief, whether orally or in writing, is made, however, it can “reverse the de-objectifying work of pain by forcing *pain itself* into avenues of objectification” (6). Writing, thus, can restore language and reverse the unsharability of pain.

6 The healing capacity of writing and storytelling is not limited to the restoration of language, however; writing can also reestablish the order of things. As illustrated above, intense grief is “world-destroying” and leads to a sense of alienation and to a breakdown of the self. Time and space are no longer perceived as coherent structures but rather as fragmented phenomena—things no longer make sense, and the self loses its power to perceive and explain itself and the world in a meaningful way. Storytelling can reverse this process. Turning a series of disconnected and chaotic experiences into narrative, the narrator can arrange hitherto unrelated events and emotions in a coherent order of before and after, cause and effect, self and world. Rather than being overwhelmed by experience, a narrator can *interpret* experience and create and identify symbols, themes, and structures that help him or her to reconstruct the world. Turning experience into story, in consequence, does not

simply describe and mirror reality; rather, Roland Barthes points out, narration “ceaselessly substitutes meaning for the straightforward copy of the events recounted” (119). Narrative, thus, *produces meaning*, not because it rewrites or willfully distorts reality, but because it extracts patterns from a seemingly chaotic accumulation of experiences, as the philosopher Paul Ricoeur suggests:

[T]he activity of narrating does not consist simply in adding episodes to another; it also constructs meaningful totalities out of scattered events. This aspect of the art of narrating is reflected, on the side of following a story, in the attempt to ‘grasp together’ successive events. The art of narrating, as well as the corresponding art of flowing a story, therefore require that we are able *to extract a configuration from a succession*. (278)

7 Drawing on Ricoeur’s theories, Byron Good uses the term *narrativization* to describe this organizing potential of storytelling in relation to stories of illness and pain. “Narrativization,” Good claims, “is a process of locating suffering in history, of placing events in a meaningful order in time. It also has the object of opening the future to a positive ending, of enabling the sufferer to imagine a means of overcoming adversity and the kinds of activities that would allow life experience to mirror the projected story” (128). Through the process of narrativization, thus, narrative “humanizes time and action” (Klugman 145) and facilitates the realignment of biographical discontinuities (cf. Becker 97; Rubinstein 259; Gee 11).

8 This healing potential of narrativization can also affect and restore the narrator’s self after the loss of a relational anchor. Telling a grief narrative, Craig Klugman notes, “often helps the narrator come to a new understanding of himself or herself and arranges the pieces of the puzzle in such a way that life can be reconstructed” (176). In writing or telling, then, mourners cannot only tell the story of the deceased, they can also rewrite their own stories and redefine themselves and their roles in community and family life.

9 The self, in consequence, shapes and is shaped by the act of writing (cf. Allister 14). The often experienced need to write and to talk about grief and illness may be connected to this inherent potential of narratives to restore the self and the world after a loss. Writing as such will certainly not miraculously dissolve the pain of mourning; it can, however, be part of the healing process, and it can shape and influence that process as well.

Printed Grief: Doris Lund’s *Eric*

10 One of the most popular grief narratives of the last few decades is Doris Lund’s *Eric*, in which Lund describes her seventeen-year-old son’s battle with leukemia. First printed in 1974, Lund’s narrative was translated into twenty different languages, turned into a TV

movie, and republished in various forms and editions (the narrative was included in the *Reader's Digest Condensed Books* series, for example, and portions have appeared in *Good Housekeeping* or *Parents' Magazine*). In 1989, Lund added an additional afterword, in which she comments on her own narrative and describes how both the treatment of leukemia and her life have changed since the publication of *Eric*.

11 From a literary critic's point of view, Lund's narrative is a relational autobiography. This term was originally introduced by Susan Stanford Friedman in 1985 to describe the differences between self-centered male autobiography and community-oriented life-writing published by women (cf. Smith and Watson 201). Friedman argues that women's "awareness of group identity as it intersects with individual identity is pervasive. Instead of seeing themselves as solely unique, women often explore their sense of shared identity with other women, an aspect of identification that exists in tension with a sense of their own uniqueness" (44). In *How Our Lives Become Stories* (1999), Paul John Eakin convincingly illustrates that this sense of a relational identity is by no means restricted to female writers, but rather a feature which characterizes male and female autobiographical writing alike, but which often has been overlooked in the past in the works of male authors (55-58; cf. Smith and Watson 201-02).

12 This shift in autobiographical criticism from the autonomous, self-sufficient self to a self that develops and defines itself in relation to others does not only redefine traditional genre categories—after all, relational autobiographies blur the line between biographical and autobiographical writing (cf. Eakin 58; Couser 156)—it also offers a new theoretical basis for the analysis of grief narratives. If, as critics such as Eakin maintain, the self defines itself in relation to others, the loss of such a "relational anchor" (Klugman) profoundly disturbs and uproots the world of the self. Grief narratives, in consequence, cannot only be defined by their topic—as narratives dealing with death and grief—but also as narratives that try to re-root the self in a new relational network.

13 Doris Lund's autobiographical account is such a narrative, which does not only recount and interpret a son's illness and death from a mother's perspective, but also depicts the hesitant reconstruction of a mother's self after her son's death. As most illness and grief narratives, Lund's story begins with the first symptoms of Eric's disease, which develop suddenly and unexpectedly, and hit a young man overflowing with vitality, energy, and strength:

GOOD FRIENDS HAVE SAID, "But how did it begin? You must have seen it coming." No one could have seen it coming. This had been a summer like many others. We live[d] in a small Connecticut town in a house just a block from the beach

[...] [and] the front hall that September was, as usual, full of sand, mysterious towels that didn't belong to us, and an assortment of swimming fins, soccer balls, and basketballs. [...] Eric, seventeen, was packed and ready to go off for his freshman year at the University of Connecticut. [...] One late afternoon as I went through the house watering the plants, I found Eric stretched out on the living room couch. I knew he'd been running earlier up at the high school track, yet there was something new in his languid sprawl that made me pause. It was rare to see Eric lying down. (1-2)

This scene, located at the very beginning of the story, illustrates the process of narrativization and the literary character of Lund's account. Even though the narrative is organized chronologically, it is not a journal but a retrospective interpretation of past events. Retrospectively, the summer day described above is identified as the beginning of Eric's disease. Even readers who do not know yet what the book is going to be about will not miss the literary cues that are given here—something is wrong with that seventeen-year-old boy, and this summer is going to be different from those that preceded it; readers will read the next pages with a sense of foreboding.

14 The difference between a journal entry and a retrospective account becomes evident in these lines. Back then on that summer's day, Eric's mother might have paused when she saw her son lying on the living room couch, but it did not, as she herself describes in her account, occur to her that her son was seriously sick. She blames his exhaustion on nervous excitement ("Tension, I thought. Going to College is a big jump" [2]) and the "hot and muggy" (3) weather instead. The beginning of Eric's disease, in consequence, is visible only in retrospect, and while there were probably unnoticed symptoms before, Lund chooses this particular afternoon as the beginning of her story because her son's exhaustion that day is the first event that she perceives as causally linked to Eric's illness. Rather than a record of events, Lund thus offers a narrativization of events, and she uses literary strategies (tension, insinuation) to organize her experiences.

15 On the following pages, Lund further develops these narrative strategies. Rather than focusing on the progression of Eric's disease and the moment of its diagnosis, for example, Lund interweaves these observations with descriptions of Eric and his past. Eric is introduced as a *character*—with a past and dreams, fears and flaws, strengths and ambitions—rather than as a son, whose familiar presence does not require further explanation, and Lund introduces the other family members in a similar manner. These narrative strategies are necessary to allow Lund's readers to follow her account, of course, but they are also part of the process of narrativization, as they embed Eric's story within a pattern of temporal, spatial, and causal coherence, and firmly locate him and his role within the network of his family.

16 As illustrated in the previous section, narrativization does not only create a coherent pattern, it also creates meaning, and this attempt to “*extract a configuration from a succession*” (Ricoeur 278) is also part of Lund’s narrative. Lund does not only describe her son’s battle, she also uses his fight to discuss existential questions of life, death, and living, and her son increasingly becomes a symbol of a life lived to the fullest in spite of adversity and pain. This image is established right at the beginning of the narration, only a few weeks after Eric’s initial diagnosis. Both angry and heartbroken when her son stubbornly insists on going to a football game on a freezing cold and wet day “with antibiotic pills in one pocket of his black loden coat and leukemia pills in the other” (20), Lund suddenly realizes that Eric needs to live *now*, no matter the risk, if he wants to live at all: “I watched [Eric leave], and I was changed. In that moment I began to understand. Now might be all he would ever have. He had to live his life. And living meant running risks. [...] There was no longer any ‘sure.’ I accepted the terrible precariousness of his life from that moment. I let go and said, ‘Eric—*live!*’” (21). Lund accepts at this point that, despite his condition, Eric is no longer a boy but a young man, who wants and *needs* to live his life independently and without restrictions. He refuses to accept his illness as a limitation and lives with and in spite of it.

17 This incredible will to live is an important theme of the narrative and helps Lund to reevaluate her son’s fate. Eric might have died young, but his life was full and complete nevertheless. Reflecting on her son’s early death, Lund writes: [Eric] saw the marvelous opportunities in *minutes*. One whole good day was a feast. [...] In spite of the fact that much of his youth had been spent fighting to live, the world was beautiful with possibility for Eric. And now I find it is more so for me. Eric’s death is not the end of joy. It’s somehow a chance for another start. I hear his favorite Chicago record still playing. “The Beginning.” (334) Eric’s life, these lines insist, was neither incomplete nor in vain. His death is indeed a beginning to Lund—she even uses imagery of labor and giving birth to describe his last hours (cf. 312, 323)—and she links this idea not only to her own life but also to that of others by embedding Eric’s individual fight within the larger context of the fight against cancer. Eric may have lost his battle, but his fight, the last sentence of Lund’s account assures us, helped others to win theirs: “And the day would surely come when Peter [a new leukemia patient on Eric’s former ward]—or someone—was going to walk out there cured, and not have to go back. We might not be around to see it. But we were connected just the same. And Eric would be part of that victory” (335).¹ These lines clearly show that Lund does not only describe her

¹The idea that Eric helped others to survive is further developed in the additional afterword, which Lund added to her narrative in 1989. After describing the increasingly successful treatment of leukemia in the 1970s and 80s,

son's life, she *interprets* it—she extracts a configuration from a succession of events, to use Ricoeur's terminology once more—and thereby provides her experiences and Eric's fate with meaning and a sense of direction.

18 Lund's narrative, however, does not only reestablish coherence, it is also a story about the slow and hesitant redefinition of a mother's self. One of the major themes of Lund's account is Eric's growing independence. In spite of his sickness, Eric increasingly leaves his mother's care. Only weeks after his initial diagnosis, for instance, he tells his mother not to cook for him any longer because he will be "out a lot" (22). He also asks her not to do his laundry or to clean his room, and he does not want her to call his doctor anymore: "It's *my* problem. [...] I'll let you know if there is anything you need to know" (22). A few weeks later, during his second round of Chemo, Eric insists on attending a few classes at one of the nearby colleges, and, during one of his later remissions, he moves out to study at the University of Connecticut as planned and is even picked for the University's soccer team. A few months before his death, finally, Eric starts dating a young nurse named MaryLou, and the two of them develop a surprisingly mature relationship, which ends with Eric's death in his girlfriend's arms.

19 Lund insists that Eric himself is the driving force behind his growing wish for independence, but she repeatedly stresses her willingness to let him go and her approval of his choice as well. The theme here, accordingly, is not only Eric's development but also that of his mother—Lund slowly leaves her role as a mother behind and finally even allows Eric's girlfriend to take over the role of Eric's most intimate partner when she leaves it to MaryLou to hold and embrace Eric in the moment of his death, even though his parents are present as well.

20 One might object here that Lund simply describes the things as she remembers them, but her choice to focus on Eric's growing independence and her willingness to let him go—rather than on his medical condition or moments of dependence and intimacy between mother and son—implies a redefinition of Lund's role as a mother as well. Back when her son was still alive, Lund was *forced* to let him go, both because Eric insisted on his independence and because cancer finally claimed his life. After his death, however, when she focuses on her own development and her approval of Eric's decision, Lund not only retrospectively endorses

Lund refers to a conversation with one of Eric's oncologists, Dr. Victor Grann, to link Eric to that success story: "'Eric, and the young patients of his generation, made a tremendous contribution,' Victor assured me. 'We were able to tap them for all sorts of information, study our successes or failures, and make careful judgments about what to try next time'" (340).

Eric's decision, but also redefines and rewrites her own role in Eric's life; in her narrative, she *lets* him go and is once more in charge of both her narrative and her life.

21 In her autobiographical account, Lund does thus not only tell her son's story; she also redefines herself and her position after her son's death, and she provides Eric's short life with meaning and a sense of closure. *Eric* is, in consequence, not a narrative about grief but rather a story of how grief can be overcome. Lund's decision to write and publish Eric's story was probably not the only factor that contributed to this healing process; narrativization, however, certainly helped her to transform the experience of her son's death into a story of life.

Virtual Grief: www.skeleigh.com

22 At a first glance, Sharon Barry's blog www.skeleigh.com is very similar to Doris Lund's *Eric*. This webpage, too, chronicles a son's death and is written from the perspective of a mother. Like Eric, Barry's son Keeghan spends much of his young life fighting, and he, too, refuses to give up and lives with and in spite of his illness. Sharon Barry documents the last two years of Keeghan's life on an almost daily basis and complements her written descriptions with more than 400 pictures and some videos of her son and her family. Like a conventional grief narrative, Barry's blog focuses on her sick and dying son, and her story does not only start with the first symptoms of Keeghan's tumor but, like Lund's account, also comes into being because of this disease.²

23 Even though Barry's blog resembles traditional printed grief narratives such as Doris Lund's *Eric*, however, there are many considerable differences. From a literary critic's point of view, blogs seem to be most closely connected to diaries. Like diaries, blogs are updated on a regular basis, and they resist the retroactive interpretation of events—the experiences of a day are discussed in connection to the past only, and an anticipatory interpretation of these experiences is impossible (cf. Smith and Watson 193; Culley 221). Fears and hopes may be directed toward the future, of course, but since these future-oriented elements can only be discussed as suspicions and expectations, the past is the only reliable interpretative basis for blogs and diaries alike.

24 A closer look reveals, however, that blogs are *not* like diaries or other forms of printed life writing. In contrast to most published diaries, for example, blogs are largely unedited. When published by the author, diaries are usually revised—uneventful or too private entries may be removed, passages may be shortened, and explanations and comments for the

² At the bottom of the section "The Beginning," Barry explains why she decided to start a blog focusing on her son's condition: "On May 9th, I started this website as a way to keep friends and family notified of Keeghan's progress. Little did I know it would turn into such an epic novel!"

audience may be added. Blogs, by contrast, are published almost immediately, and this sense of immediacy clearly distinguishes them from the private seclusion of diaries. In addition, even if a diary is published unedited (as it is sometimes the case with posthumously published diaries), diaries follow the natural flow of events: they start at a certain date and move forward in a chronological order. Reading diaries is a linear activity in consequence since nothing interrupts the consecutive description of experience. Blogs, by contrast, are published simultaneously chronologically (as one and the same entry is to be read from top to bottom and follows a chronological order) and in reverse-chronological order (as the newest entry can be found at the top of the page). In addition, rather than linearly describing experience, blogs often work on several levels at once. Hyperlinks, for example, can connect the different sections of a webpage, and they can also incorporate other webpages, directing the reader to entirely new narratives and opening up alternative itineraries of reading. Moreover, the readers of a blog often create a collaborative text of their own in the webpage's guestbook. This alternative text comments on the blog and sometimes extends it (hyperlinks, additional narratives, etc.), but it is, in turn, also often picked up and commented on by the blog's author in his or her entries. This interactive structure also clearly distinguishes blogs from diaries or any other form of life writing.

25 Unimportant as they may seem, these differences between blogs and traditional forms of life writing are important because they redefine the narrative process. As illustrated in the previous sections, writing can help writers to deal with their grief because the process of telling a story in retrospect facilitates narrativization. Narrativization can reestablish coherence, and it can help the writer to interpret his or her own story and thereby to provide it with meaning. As the writing process in a blog is fragmented (separate updates covering a very limited amount of time) and directed from a limited point of view (no considerable temporal distance to the events described), narrativization is not—or only in a very limited way—possible in a blog.

26 The difference between a traditional grief narrative and a grief blog can be seen in the two sections “The Beginning” and “The Journey” on Barry’s webpage.³ The chapter “The

³ Barry’s webpage is subdivided into eleven sections, which can be accessed via the site’s navigation menu. The first section entitled “The Journey” consists of entries ranging from May 9, 2006 to January 22, 2009 and documents Keeghan’s treatment, his death, and the time immediately following his death; one of the earlier entries (May 22, 2006) is written by Keeghan himself. While the section “The Journey” consists of almost daily updated short entries in reverse-chronological order, the second section entitled “The Beginning” offers a coherent narrative, which retrospectively describes the onset of Keeghan’s disease and which covers the time period between March 10, 2006 and May 9, 2006; this part of Barry’s webpage was added almost a year after Keeghan’s initial diagnosis and thus several months after her first blog entry. The section “Moving Forward” consists of single entries in reverse chronological order again. No longer updated on a daily basis, this section

Beginning” is actually not a blog but a coherent piece of writing without any subdivisions. Like Lund, Barry relies on literary strategies in this section, and she, too, uses her account to embed her son’s story within a pattern of temporal, spatial, and causal coherence: “Ok, I said a few weeks ago that I was going to do this and I just haven’t made myself follow through ... but with the anniversary of Keeghan’s diagnosis coming up, I decided it needs to be done. So, how did this all start? Funnily enough, it started with a broken nose. Sort of.”

27 Barry goes on describing how Keeghan broke his nose at school in March 2006 and started to develop headaches several weeks later. Suspecting that his facial injury may not have healed properly, his physician ordered an MRI, which finally revealed that Keeghan was suffering from a brain tumor and that the situation was already life-threatening due to the tumor’s size and location. Without any warning or time to grasp the situation, Keeghan was transferred to a pediatric intensive care unit and finally flown out to Houston, where the tumor was surgically removed; two days later, the Barrys had to accept the fact that Keeghan’s brain tumor was malignant.

28 The narrative elements are quite visible in this section of Barry’s blog. First of all, Barry establishes order by giving both her account and Keeghan’s illness a clear starting point. Even more than in Lund’s account, this starting point is random since the broken nose is actually *not* related to the tumor at all. Retrospectively, however, the broken nose is the felt beginning of Keeghan’s illness, on the one hand because it finally leads to the discovery of the tumor, and on the other because Keeghan is brought into contact with the world of hospitals, sickness, and pain for the first time.

29 As Doris Lund, Sharon Barry also relies on stylistic devices such as tension and insinuation in her account. Everything she mentions in this section is driving at Keeghan’s (later) condition: Barry leaves out unimportant days and details and even comments on that choice (“*Fast forward a few weeks ...*”), she uses bold print for emphasis, (“**‘Mrs. Barry! Your son has a brain tumor’**”), and she hints at later developments. (When she describes Keeghan telling the paramedics on his way to the airport that “he had never even had blood drawn until just a few days ago, and now look at everything he’d had done!” for example, Barry comments: “Little did he know, eh?”). Surprising and shocking as the events may have been at the time of Keeghan’s diagnosis, Barry’s text *expects* them, and integrates them into a coherent spatial, temporal, and causal order.

covers the time period between January 22, 2009 and the present and describes the Barry family’s life after Keeghan’s death. These three text sections are accompanied by a video page, a guestbook, a contact form, and five picture pages (four regular picture pages paralleling Barry’s written entries, and one page dedicated to a family trip to Ireland).

30 Moreover, Barry uses themes to structure her account and to provide her experiences with meaning. Humor, for example, is a very important element in Barry's account, and rather than focusing on medical procedures and test results, Barry focuses on the jokes the family members share with each other in spite of Keeghan's life threatening illness. Similarly, family support is a very important topic; Barry stresses the significance of her husband, her close relationship to Keeghan, and the unusually close and mature relationship between Keeghan and his sister Maxx. All these elements structure Barry's account and clearly point to various sources of support. The situation may be dire, but Barry's account in this section speaks of strength and confidence, and she is, in spite of everything, in charge of the situation.

31 As Lund, Barry does not thus offer a report in the section "The Beginning" but rather a retrospective narrativization of events. This situation changes remarkable, however, as soon as Barry starts to blog about her experiences. Suddenly, things come unexpectedly, and Barry is no longer in control of the narrative. On December 27, 2007, three months after Keeghan had been considered cured after his first round of treatments and two days after the doctors started to suspect a relapse, Barry writes:

Very quick update. Keeghan had his spectroscopy scan yesterday, and the PET scan today. [...] I spoke with Keeghan's oncologist briefly today. Honestly, the information that I got from him felt more like bullet statements than answers.

- spot larger
- enhances differently
- new tissue · will consider sending to Houston to M.D. Anderson if surgery necessary
- need to schedule follow-up appointment with neurosurgeon

So, we won't have true answers until next week. [...] I won't lie. I'm terrified. [...] My mind is fried just from all the "what if's."

Torn between desperation and hope, Barry's language becomes monosyllabic. She no longer has the power to order and explain her experiences because she does not know their outcome yet; rather than writing her story, she seems to be a character of a story someone else is writing. In a blogged narrative, it seems, narrativization is not possible any longer—a period of a few days may be overlooked and structured, but since the narrative is always open-ended and dependent on an uncertain future, it can never achieve the same degree of closure, structure, and coherence as a text written in retrospect.

32 The concept of narrativization is thus no fruitful theoretical basis for the analysis of blogged narratives of illness and death. Instead, Byron Good suggests, Wolfgang Iser's reader-response theory might offer a useful methodological approach. Focusing on oral illness narratives, Good notes: It is my contention that reader response theory has special relevance for our investigation of illness narratives. The narrators of most illness stories [...] are

typically in the middle of a story. The narratives they produce are more akin to the “virtual text” of the reader of a story than the “actual” narrative text of a completed novel. They are stories that change as events unfold. They point to the future with both hope and anxiety, and they often maintain several provisional readings of the past and the present. (144) For both the reader of an unknown text and those trying to describe an ongoing experience, Good argues, the story is incomplete, and plot is “less a finished form or structure than an engagement with what has been told or read so far in relation to imagined outcomes that the story may bring” (145).

33 Byron Good, one must note here, is analyzing oral interviews from an anthropological perspective, and he interviewed patients who were suffering from chronic (but not life-threatening) diseases. These interviews were conducted as part of a research project, and Good respects his patient’s privacy by using pseudonyms rather than their real names, and he also only publishes short excerpts from his patient’s narratives rather than their complete stories. Even though Good speaks of “illness narratives” when he describes these interviews, the narratives he refers to have thus little in common with traditional forms of life writing. In spite of this anthropological interest, however, Good’s analysis is extremely interesting in connection to literary and narrative analyses of grief and illness blogs since blogs resemble Good’s interviews in one important aspect: in both cases, the narrating subject is still part of the story it tells.

34 This immediate perspective precludes narrativization and turns interview partners and bloggers alike into readers of their own stories. Like readers, both evaluate the past in light of an emerging present, and they both try to make sense of their situation using an available body of typical plots drawn from their cultural repertoire (cf. Good 146; 153). They are, to use Goods terms, “still actively engaged in ‘emplotting’ the condition from which they suffer” (146). Emplotment according to Good’s definition—“the activity of a reader or hearer of a story who engages imaginatively in making sense of the story” (144)—is similar to the process of narrativization as both activities try to make sense of a situation. In contrast to narrativization, however, emplotment tries to influence the outcome of a still open situation, as an unfinished text always offers multiple readings and perspectives and thus allows for different interpretations. As long as death has not set a definite end to a life, healing is thus still possible for those telling an illness narrative (and those in the middle of reading it), even if miracles are necessary.

35 While printed grief narratives talk about the past only and evaluate this past from the detached position of the present, both grief blogs and Good’s illness interviews are

characterized by “a teleology, a sense that the story is going somewhere. The narratives are aimed not only at describing the origins of suffering, but at imaging its location and source and imagining a solution to the predicament” (Good 121). As long as the story is still incomplete, this sense of direction can provide the narrator’s story with meaning, and it can structure experiences and events in a similar way as the process of narrativization. “When the imagined outcome of the story fails to materialize, however, when suffering is not relieved [...] the self is threatened with dissolution” (Good 121).

36 This dissolution of the self expectedly becomes evident in Barry’s narrative with Keeghan’s death, the point of no return, which once and for all destroys the future Barry is hoping for so desperately. During the first few days after Keeghan’s death, Barry’s entries are still long and flowing and, to a certain degree, characterized by a sense of thankfulness for all the support provided by family, friends, and unknown guestbook signers. Ten days after Keeghan’s death, however, grief directs and controls Barry’s account: 10 September 2008 – 10:15 How does it feel to “move on” with your life after your child dies? It sucks. [...] It hurts. So much. I want him here. I want to feel him in my arms. I want to hear him yell at the dog to stop laying [sic] on his feet. I want everything that I can’t have. The anger and grief expressed in these lines does not leave Barry’s blog; if anything, it gets stronger, and Barry is keenly aware of Keeghan’s absence and the meaningless rhetoric of comfort and support. Moreover, writing loses its meaning-providing potential, and Barry obviously cannot see any purpose in her blog any longer, either: 4 December 2008 This is (hopefully) going to be a quick, and somewhat final, update. After this, I am no longer going to be updating here unless it is with some big announcement (which I’m not expecting many of in the near future). [...] This journey hasn’t ended, and what is here on the site will remain here. But my updates are over, as they are no longer helpful to me in any way. [...] 28 December 2008 Nothing feels the same. I have received many emails from people in the past few weeks, and I hope that everyone can forgive me for not replying. It isn’t that I am ignoring you. I just can’t deal with it all right now—answering emails, talking on the phone, accepting words of comfort—it’s too much. I thank you for your kind words, all of you. But please understand that I am treading water here. I keep myself busy every day just to keep the breakdowns at bay. That doesn’t mean I don’t ever breakdown—I do. Every. Single. Day. [...] 24 February 2009 I never know how to start posts here anymore. [...] Sharing the highlights of everything that was Keeghan was such a joy. [...] [T]hat was my life raft. Getting it all out of my head kept me afloat. Also, I felt certain that keeping Keeghan’s story alive would somehow keep him alive. All of that is gone now. [...] [I]t is very rare right now for me to be able to write for any

length of time without completely falling apart. [...] The pain of losing Keeghan has not lessened in any way over these six months. In fact, it has become so much worse. I think for those first few months we were all in shock. Numb. But now that the pain is being felt in its entirety, it's [...] horrible. Crippling even. Therefore, I find myself thinking in bullet statements. [...] Even the way I think has been affected by the loss of Keeghan.⁴

37 In contrast to Lund's narrative, which is the story of a mother's coming to terms with her son's death, Barry's account is a story of unfiltered grief, and it is characterized by an acute sense of loss, which threatens to deconstruct both language and writer. These are not the sobs and shrieks Elaine Scarry describes in her study of torture victims; to a lesser degree, however, the pain of grief seems to make language similarly inaccessible, and the experience of grief implies the same "unsharability" that Scarry connects with physical pain (cf. 4). Without a certain distance to her own experiences, narrativization is thus not an available strategy for Barry, and rather than documenting a process of healing, Barry's blog chronicles her growing sense of desperation. While both Lund and Barry describe a very similar situation, their narratives thus take different forms, leading to two very different stories.

Blogged Healing?

38 One might argue here that the main difference between Doris Lund's *Eric* and Sharon Barry's blog is time. Barry never stops writing (she even posts an entry a few hours after her son's death), and her blog is a seismograph reflecting the slow and painful process of grief. The blog shows a writer who has not yet succeeded in redefining her position after the loss of an important relational anchor. Lund, by contrast, published her narrative approximately two years after her son's death, which left her more time to deal with her loss and to come up with new perspectives. As illustrated above, Lund successfully redefined her role; this redefinition does not take away the pain of a grieving mother, but it provides her narrative with a sense of healing and acceptance, which Barry's blog is (yet) lacking.

39 The difference between the two narratives, however, is not so much time as the process of writing and publishing. Even if Barry is going to come to terms with her son's death at some point—and several of Barry's more recent entries indicate that she will—her blog will never be similar to a conventional grief narrative as it will always be an open-ended report characterized by emplotment rather than narrativization. Blogs are, in consequence, *not* simply an alternative variant of printed forms of life writing differing from

⁴ All passages quoted above are all part of longer entries, and there are several updates in between those entries as well.

conventional (auto)biographies only as far as the *mode* of publication is concerned. As the comparison of Lund's and Barry's narratives reveals, the mode of publication fundamentally influences the writing process and thus the nature of the written text.

40 This difference, it seems, has been neglected for the last few years. In the past decades, most scholars have focused on content-related questions and the relation between self and world in their attempt to define and categorize different forms of life writing. One of the standard reference works on life writing, Sidonie Smith and Julia Watson's *Reading Autobiography*, for example, lists fifty-two different genres of life narrative. The authors differentiate between *autopathographies* (autobiographical narratives dealing with disease and disability), *ecobiographies* (autobiographical texts in which authors define themselves in relation to nature), or *captivity narratives* (narratives told by [former] captives or hostages), for instance, but they do not mention blogs or other forms of virtual life writing (see Smith and Watson, 183-207). If web-based forms of life writing are considered at all, critics usually focus on the new technological possibilities of virtual writing (technological interactivity etc.) or on new forms of self-representation such as *Second Life* or social networking platforms such as *Facebook*.⁵

41 As the comparison of Barry's and Lund's narratives reveals, however, we do not have to examine completely new kinds of self-representation on the Internet in order to find new forms of expression. Blogs, even if they consist of nothing but written words, are based on a different mode of writing and publishing. Virtual and printed texts do not only differ in terms of their technical and formal preconditions—like an audio book and a printed book—but their different genesis decisively influences the way in which these two different forms of writing mediate experience. The writing process thus shapes a text as essentially as traditional narrative categories such as topic, imagery, or perspective. Blogs, therefore, do not just mirror familiar forms of writing on a computer screen, but they reinvent and redefine these forms, creating new stories and new narrative modes. This innovative potential of virtual forms of life writing has largely been ignored in the past; as the comparison between Lund's and Barry's narratives reveals, however, the Internet and its modes of expression certainly deserve further critical attention.

⁵ For a discussion of social networking platforms, see, for example, Westlake and Papacharissi; for new forms of self-representation, new technological possibilities, and a discussion of privacy in online, see McNeill, Zalis, Killoran, Kennedy, and Sorapure.

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My Quest through Chaos: My Narrative of Illness and Recovery

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Abstract:

Stories of people trying to figure out who they are following illness are both popular amongst readers and vital to the author's recovery. This article is an illness narrative and an exploration of illness, narrative, recovery, and critical disability studies. Using my own experience of having a massive stroke as an 18-year-old, the article considers narrative structures present in a series of journal entries, video diaries, letters, and blogs to reflect on the importance of narrative throughout my recovery. My story has evolved through the dominant narrative structures of the illness narrative as outlined by Frank (1995)—chaos, restitution, and quest. These narrative types display the relationship between narrative and culture, and emphasise the complexity of illness. Telling illness narratives is a valuable means of recovery when the body becomes what the individual never expected it would—damaged. Narrative is vital, as the ill persons work out their changing identity and position in the world of health, continuing when they are no longer ill, but remain marked by their experience. This article connects the (my) autobiographical to the social, political and cultural.

Writing testimony, to be sure, means that we tell our stories. But it also means that we no longer allow ourselves to be silenced or allow others to speak for our experience. Louise DeSalvo, *Writing as a Way of Healing* (216)

Stories of people trying to sort out who they are figure prominently on the landscape of postmodern times. Those who have been objects of others' reports are now telling their own stories. As they do so, they define the ethic of our times: an ethic of voice, affording each a right to speak her own truth, in her own words. Arthur W. Frank, *The Wounded Storyteller* (xiii)

Introduction

1 Seriously ill people need to tell stories: to their doctors, to their family, to their friends, to themselves. This article is both an illness narrative and an exploration of illness, narrative, recovery and critical disability studies. Telling illness narratives is a valuable means of recovery when the body becomes what the individual never expected it would—damaged. Narrative is vital, as the ill person works out their changing identity, and position in the world of health, continuing when they are no longer ill, but remain marked by their experience.

2 Following the tradition of illness auto ethnographers (Frank, *The Wounded Storyteller*; Ettore; Rier), this article critically examines the role of narrative throughout recovery from serious illness or trauma by connecting the (my) autobiographical to the social, political and cultural. The paper is divided into six sections and explores three different narrative structures commonly adopted by people telling illness narratives and the way they are shaped by culture.

I begin by establishing illness narratives as a field of enquiry within critical disability studies and introduce my own experience with life threatening illness as the motivation for storytelling. The next three sections of the paper utilise Arthur Frank's chaos, restitution and quest illness narrative structures in conjunction with Joseph Campbell's hero's journey to argue recovery is a process of travelling through and returning to these modes of storytelling. Restitution desires the past and prevents recovery while chaos does not consider recovery. When the wounded storyteller arrives at the quest narrative and draws together chaos and restitution with a sense of purpose, recovery can be achieved. Although these narrative types are not the only structures available (cf. Couser), I introduce them here as an opportunity for reflexive self research. The focus then shifts to the recent emergence of illness narrative blogging to consider their cultural significance before exploring stigma and resistance to the telling of illness narratives and offering conclusions towards this end.

3 Although influenced by medical sociologists such as Arthur Frank and Elizabeth Ettorre, I write this article as a critical disability theorist seeking to refine the social model of disability in order to recognize the impact of impairment and illness on those who find benefit from a social understanding of disability. The social model of disability sees disability as the negative social reaction to impairment which has resulted in disempowerment and an inaccessible environment. This model has traditionally neglected to include people suffering from illness or debilitating impairments. I proceed alongside recent calls to broaden the scope of theorization to reflect on biology and the difficulties that result from illness and impairment and can't be blamed purely on a disabling society (Shakespeare 39).

4 Like Mitchell and Snyder (2), I choose to use the terminology "people with disability" throughout this paper rather than "disabled people" which is favoured by social modellers. Via this terminology I recognise disability as more than a medical problem yet acknowledge the body (including medicalized experiences) within my theorization of disability and social construction. Mitchell and Snyder's definition works well with Goffman's notes on stigma creation and encompasses people experiencing illness. By drawing on a series of journal entries, video diaries, letters, and blogs, my narrative and argument moves between and alongside the chronology of the catastrophic event which has motivated both my research and writing and personal perception of the world. While I have attempted to record months as accurately as possible, the exclusion of dates from some of the reflective material arises from the chaotic experience of my illness and recovery. I did not always record the date on which I wrote something, perhaps because a future was so out of sight and in many ways time did stand still.

Illness Narratives

5 Monday 24 March 1997 I had a massive stroke and my life depended on controversial surgery. Eventually my ability to walk would depend on exhaustive rehabilitation. I was 18 years old. I never expected such a thing would happen to me. Recovery seemed very long and required a total reworking of who I believed myself to be:

On Saturday it was exactly 10 years since I had a stroke and my life changed forever. And that day was the first 'anniversary' that I wasn't sad. I had a really awesome day. I read somewhere that you're more likely to have another stroke within 10 years of your first one, so I dunno if that's why I was feeling good or if it's cause I realise that my life 'changes forever' almost every year... (Unpublished Livejournal blog 26 March 2007)

6 According to Bonner and McKay, an illness narrative is most often autobiographical in nature and “recount[s] an individual’s experience with accident and disease, usually tracing the situation from onset through diagnosis, treatment and recovery” (156). Illness narratives allow damaged bodies a privileged means of recovery and a way to navigate the worlds of health and illness. People enter into narrative predominantly out of a desire for self-exploration, but also to help others going through a similar experience. Many note that in the process of telling their illness narrative they experienced healing and a renewed identity (see Sherr Klein; DeSalvo). Illness narratives adopt different structures but can usually be categorised as chaos, restitution or quest (Frank, *The Wounded Storyteller* 53).

7 The chaos narrative lacks reflection as recovery is not a recognisable possibility, while in the restitution narrative, a recovery of the self as it existed before the onset of illness is emphasised, and restoring health is the basis of the storyline. Finally, in the quest narrative, the illness is seen as a calling and recovery is dependent on acknowledging a changing world view and sense of self (DeSalvo 199). Combining these narrative structures documents and aids recovery. These narrative types move alongside each other as the story continually unfolds (Thomas-MacLean 1648).

8 I have used the documentary film medium twice to document my illness narrative. However, it was not until I had finished the second film that I felt I had personally gained something out of it, emerging as a changed person. During the making of the second film I described it as:

A story about Katie Ellis a 21 year old who after suffering a massive stroke at the age of 18 wants to find healing by turning her stroke into a documentary to gain insight enabling her to get on with her life as someone new. (With Both Hands Directors' Statement April 2000)

9 I wrote that the success of this aim would simply be in completing the documentary. However, I had already completed a documentary the previous year; if the success was simply in making the film, why was I not satisfied? I initially described this earlier film in these terms:

An 18-year-old girl has a severe stroke. She is not affected mentally but physically she is left totally paralysed on one side of her body. She is placed in a rehabilitation hospital with other stroke patients about three times her age. She feels no one else understands but internalises this feeling. At first she is very outwardly depressed and keeps to herself in the hospital and doesn't associate with the other patients but as time goes on and she improves she begins to rely more on the other patients than her friends. She has been told that she will never fully recover and that her arm and foot in particular will probably never actively function again. She knows that this is true but cannot admit it to other people let alone herself. (In Between Spaces Directors' Statement August 1999)

10 While at this stage I was beginning to address thoughts and feelings with detailed accounts, I don't appear to be writing about *my* personal experiences. Although both documentaries were about myself—and I had control over what went into each—there is an obvious difference in approach. I wrote about wanting to remake the film:

I wanted to tell my story not just to work out my changing identity but also to guide others. Restoring my health was the basis of the story line of a previous film I had made. While at first this story seemed cathartic, I needed to make a film where I linked my feeling with events in a detailed way. When I made this link a sense of purpose emerged. My struggle became an opportunity for journey. (With Both Hands Directors' Statement February 2001)

11 The need to turn these experiences of illness into stories is not uncommon: “people tell stories not just to work out their own changing identities, but also to guide others who will follow them. They seek not to provide a map that can guide others—each must create his own—but rather to witness the experience of reconstructing one's own map” (Frank, *The Wounded Storyteller* 17). I felt the need to tell my story:

I felt a responsibility for testimony, to give it voice, to share my story for use so that it was not wasted. The quest story changed my relationship with my pain. I preferred to use it rather than regret it. (With Both Hands Directors' Statement November 2000)

12 Using rather than regretting my illness involved giving voice to my experience via narrative and I began with the chaos narrative, perhaps the most uncomfortable and least heard of the three structures Frank describes.

Chaos Narratives

13 When serious physical illness or injury happen in a culture that takes health for granted, it is a shock that makes the body unfamiliar to the individual and thus brings about a total re-imagination of the 'self' (Nettelbeck 153). People often retell their stories by venting their feelings through the chaos narrative. In the chaos story illness stretches on forever as time has no sequence, and the writer does not associate with what s/he is writing. There is no future in sight. It is as though the story is being forced to go faster in order to catch the suffering in words (Frank, *The Wounded Storyteller* 102):

I'm trying desperately to be the girl I used to be but there was nothing wrong with her. She wasn't trapped in a body that doesn't work. Sometimes I think I did die and this is actually hell. I'm so scared I might not get better but how can I tell myself this, let alone other people? Is this really a life wasted? No one really understands what I'm going through, but how does feeling sorry for myself help? Now I'm living in a rehab hospital, depending on people I don't know to wash, dress, and toilet me. Sometimes it gets me down that everyone in this hospital is so much older than me. I'm only somewhat comforted when told that younger people have a higher chance of recovery, because I'm also constantly reminded how abnormal it is for an 18-year-old to have a stroke in the first place. I think about what I am missing out on, all the time. (Unpublished Journal April 1997)

14 In my chaos narrative, recovery is already deemed unachievable because I have no other way of thinking about myself in the world. My present self was so different to the past, that I was experiencing myself as an "other" (Rimmon-Kenan). I have no agency; other people "do" everything to and for me. I feel out of place, perhaps already dead, a wasted life. I'm unable to receive comfort. It's not comforting that younger people have a higher chance of recovery when I know younger have a lower chance of having a stroke in the first place, and it's already happened to me.

15 In the chaos narrative, I have dissociated from my body, abandoned identification with myself. Through a lack of reflection these stories take on an 'and then and then' structure:

I'm only 18, I didn't realise 18-year-olds could have strokes; I thought that only happened to 500-year-olds. When it happened I was talking on the phone to a friend. I started to develop a headache and apparently my voice became softer and I began slurring my words and just hung up. I then took two panadol and began throwing up violently. I began looking around my bedroom for something to throw up in, as I felt too weak to walk to the toilet. It was then that my mother and two sisters found me and tried to lift me but couldn't, my dad came home and told me to put my weight on my leg and I told him that it already was. I was then driven to hospital in an ambulance. (Unpublished Journal April 1997)

16 Seriously ill people need to tell stories: to their doctors, to their family, to their friends, to themselves. The story I was telling my friends in 1997 was a combination of the chaos and restitution narratives (explored in the next section). But as yet, it didn't have a purpose:

I can't move my left side. But my face has gone back to normal, but they had to shave half my head because part of my skull has been removed, as my brain was swelling too much and I would have died otherwise. I used to wish that I had just died, because I feel that my recovery is taking too long and that no one understood. But in reality, my doctors reckon that I'm getting better really fast. Well my arm is moving a bit more. I can basically move my thumb whenever I want but my fingers aren't back yet. My foot isn't either. And I'm really stressing about that. So yeah, I'm pissed off that this has happened to me. (Unpublished Letter May 1997)

This letter begins to link feelings with detail, but still demonstrates dissociation with myself. When this link is made “the ill person gradually realises a sense of purpose, [and] the idea that illness has been a journey emerges” (Frank, *The Wounded Storyteller* 117). This letter (which I never sent) reveals that I was not seeing a future for myself yet and was relying heavily on doctors' opinions, even to the point where I was discounting my own. I was having trouble admitting that I might never fully recover the parts of my body that were paralysed. Admitting the severity of my impairment to other people was worse because I felt an intense cultural pressure to tell a restitution narrative that would reassure everyone that I was, and would be, okay:

Constantly people ask me 'how are you?' How do I answer that? I can't move properly or much really but health wise I feel normal—not sick or anything like that. Also people wish me well for a speedy recovery. While this would be great a full recovery is what I hope for. (Unpublished Journal June 1997)

Restitution Narratives

17 In the restitution narrative, restoring health is the basis of the story line. They are like a paracetamol commercial—“yesterday I was healthy, today I'm sick and tomorrow I'll be healthy again” (Frank, *The Wounded Storyteller* 77). Our society welcomes restitution narratives, encourages them because we need to believe that medicine can cure everything. The restitution narrative is favoured by people who are ill because new identities, that acutely remind individuals of their difference, are resisted.

18 During the period of my physiotherapy treatment I stopped using my journal to vent and instead started documenting what I saw as important steps towards my recovery of becoming that girl I “used to be”:

11 April 1997 Started physio

17 April 1997 Walked with two physios

05 May 1997 Walked with one physio

20 May 1997 Walked alone

24 June 1997 Walked alone 20 minutes

13 July 1997 Didn't use wheelchair all weekend

21 March 2000 I am able (bodied). I am independent. There is nothing I can't achieve

Although documenting what I experienced, these short entries in no way explain what I was experiencing or what is really involved in learning to walk again. The only time I did venture further than just one sentence was the day I walked alone for the very first time and even then all I said was: *The feeling of euphoria I experienced at that moment is describable only by the smile that was my face.* (Unpublished Journal May 1997) These entries provide evidence for DeSalvo's argument that "the implication of the restitution narrative is that our bodies can be restored to what they were like before illness struck" (198). Although discounted by disability theorists (Barnes 23; Oliver 32), the restitution narrative is nevertheless crucial to recovery because it encourages people who are ill come to terms with the world of "health" and their place in it (Radley 98). Although initially resisted, following illness or injury, individuals must redefine themselves. By reworking the restitution narrative's claim that things can return to how they were before, the quest narrative acknowledges that everything has changed.

19 The restitution story is favoured by society because it provides reassurance in the myth of body stability. However, many people with illness and disability do not fit into a restitution narrative. Although I sought to believe in restorative health via the restitution narrative, ultimately I acknowledged that illness was an experience and identity that I needed to embrace and via the quest narrative I'm able to explore an alternative way of being (well).

Quest Narratives

20 The quest story allows the ill person to give testimony and reflect on their changing identity in a culture of health. Several years after my stroke I described having my stroke without adopting the chaos structure:

I was watching t.v., and also talking on the phone and then I started feeling dizzy. I wasn't mad at my friend who I was talking to or anything; it was a normal time, normal day. So I said to her I have to get off the phone because I feel really dizzy. [...] I ran up to my bedroom and started talking really funny and just threw up everywhere. Then I had this explosion in my head, a really bad headache, worse than I've ever had before. I didn't think this was as bad as it was. I just thought it was this really weird headache that I was having and didn't realise that I was having a stroke. But I realized something was going to be different, from that moment but I didn't really realise how and how badly. I was really confused the whole time and I went and took panadol as well. It was more the pain of having it, even though it's not supposed to hurt. That's crap, because it does. And vomiting, I don't know how normal that is but that's what happened to me. That might have had something to do with me choking on panadol. Because I thought I'll take panadol and be okay. (With Both Hands recorded on 15 August 2000)

About the same event, there are significant differences in the retelling. In my chaos narrative I described events leading up to the stroke without actually writing about the moment itself,

although I have always been able to remember it. In the later description, I also noted that I realised something was going to be different, without realising what would change. The quest had begun, as I was beginning to accept my stroke was a calling, that my life would take a new direction.

21 Throughout the writing of my own quest narrative I drew on several published examples of illness narratives dealing with stroke (Newborn; Berger; Sherr Klein) while rejecting others (Leaney; Veith). The authors that I followed conceptually saw their strokes as the first stage of the hero's journey as according to Joseph Campbell; departure. According to Campbell, all narratives adopt three main stages beginning with departure where the hero leaves the ordinary world to search for a solution or elixir. In all cases mentioned the call to departure is having a stroke. Before finding the elixir in the second stage (initiation) the hero encounters trials. In the illness narrative these trials take the form of suffering, and illness. The elixir, which the hero finds in the initiation stage, is in the form of knowledge gained. This basic narrative structure corresponds with Frank's framework for illness narrative as he ultimately suggests the "crucial test of a story might be the sort of person it shapes" (Frank, *The Wounded Storyteller* 157). The hero returns to the world transformed with new strength in the third stage. The hero of the illness narrative "returns as one who is no longer ill but remains marked by illness" (Frank, *The Wounded Storyteller* 118). The illness has changed the hero, given him/ her a new perspective. Healing brings about a new perspective (DeSalvo 3).

22 The quest narrative follows the three major stages of Joseph Campbell's description of the hero's journey; departure, initiation and return. My call to departure was having a stroke. My initiation was trials, in the form of suffering and illness, enabling me to gain knowledge (elixir):

Yeah I was amazed that I was doing this all by myself. Yeah I wasn't prepared for it and I remember thinking 1st time I walked I'm gunna be so happy and then when I actually did I didn't realise I was until towards the very end and if you see the smile on my face I think that's the only way I can possibly describe it there's no words. It's still an ongoing thing it's not like you walk one day and you walk forever you have to still work at it. (With Both Hands recorded on 15 August 2000)

23 In the third stage, the hero of the illness narrative "returns as one who is no longer ill but remains marked by illness" (Frank, *The Wounded Storyteller* 118). I returned in the third stage no longer ill but forever influenced by my trials. I was changed by illness, given a new perspective. The quest story changed my relationship with my pain. When I began this journey I couldn't understand why I was chosen to take it: *Why couldn't this have happened*

to a stronger person? Unpublished Journal May 1997 I now know that I am this “stronger person” I wrote about. I would not have chosen this way, and I often wonder how I travelled it, but I would never change it either:

It's a huge part of my life, it's everything to me—that this has happened to me and that I got through it and things are pretty normal and that I can pretty much live as I would have before. It's just, there is a weakness. You could say it's like this hasn't happened to me, but it has. That's what's made me who I am now, and I am grateful for that, I am happy for that. It changed how I felt about things. (With Both Hands recorded on 15 August 2000)

This entry demonstrates the importance of not choosing one narrative structure above another, but keeping all of them. All three types are clear in this entry. Restitution: when I claim that I can live as I would have been able to before. Chaos: when I continue to dissociate myself from my body “there is a weakness.” Quest: when I recognise the knowledge I have gained. These types of experience are different from the mainstream belief in health and body stability yet cannot be attributed wholly to a disabling society. In the next section, I explore the relevance of the social model of disability to my own changing identity and offer some reflections on how illness can expand the relevance of this model.

Illness Narratives and the Social Model of Disability

24 People who are seriously ill or who experience disability as a result of illness do not fit neatly into cultural and social theories, often being positioned as the real limitation from which to escape. For example, women, gay men and lesbians and indigenous people have historically experienced a medical pathologisation that has contributed to their social exclusion. Disability activists likewise refuse any association with illness, particularly within the social model of disability which argues that most, if not all, of the problems experienced by people with disability can be solved via social manipulation. Under the paradigm of the social model of disability, impairment becomes disability because society is structured for the able bodied majority (Oliver 22):

The more I read about the social model of disability, the more I began to question my own identity. I became absorbed in the debate as it ran through every aspect of my life, often seeping into practical aspects of my research. Why, for example, were the disability studies books placed on the top shelf of my university's library? Why wouldn't my university's insurance policy cover me for overseas research travel? Why did delivery trucks park in the disabled parking bays? These disabling situations that have been left up to me as an individual to deal with, have nothing to do with my impairment. Disability is an ideological reality. (Ellis, “You Look Normal to Me” 8 June 2004)

25 As a way to maintain political power, illness and the effects of impairment have been played down under this model of empowerment (Shakespeare and Watson 5). While this strategy was integral in raising the self esteem and political awareness of the disability community, this model requires a revision to allow for the inclusion of other groups experiencing social exclusion. As Shakespeare and Watson argue, “the denial of difference is as big a problem for disability studies [...] as it was for feminism” (11). They draw on the work of Linda Birke in feminist studies to suggest the body does affect the lives of people who have impairments and to deny this is to deny a huge part of the lived experience of these people. Illness and impairment are important aspects of the personal identity of many people with disability:

I cut my long hair pretty short [and] I feel like I've reclaimed myself and have stopped trying to chase the person I was when I was 18—before I had a stroke and was forced to shave my hair off for an operation. (Unpublished Livejournal blog 24 January 2006)

This short blog appears in my Livejournal alongside longer entries that document my social life, search for an academic job, publications strategy, teaching workload and pop culture quizzes which I describe as my “journey of self-discovery.” This blog entry acknowledges that long hair is a socially constructed marker of femininity, yet recognises the significant impact losing my hair had on my sense of self and the loss of control I felt at that moment. There is also much evidence throughout this blog that although I am no longer ill, I remain marked by my illness as Frank predicts happens to people who experience and recover from serious illness:

Yesterday I was reading an article that said people who drink lots of coffee are more likely to have heart attacks. This was not good news but I thought I'd be able to screen it out of my consciousness but then I kept reading and it went on to say coffee also increases levels of the stress hormone homocystine, which can lead to strokes. Considering I've had a very very high level of homocystine which did in fact lead to stroke I felt I should pay attention. My sister Amanda tells me that I already knew this—just chose to forget. Maybe I should get a homocystine check. So today I have had one cup of coffee and one decaf. I feel my productivity slipping in very extreme ways. (Unpublished Livejournal blog 13 March 2006)

26 Blogs are interactive online reverse chronological journals that allow authors to reflect on life and the events they experience. Unlike typical diaries or journals, blogs are characterised by community, and allow others to contribute to your experiences via comments. For Michael Keren, illness narrative blogs are one of the most important functions of this new form of communication because they allow sick people to share their day by day, hour by hour feelings while gaining and sharing information and emotional support (119).

Although the experience of stroke shapes my daily perceptions, my blog is not an illness narrative blog in the strictest sense of the definition. It does however allow me an outlet to express experiences that are usually silenced by both my culture which does not wish to be reminded of body instability, and my research area which discourages any association with the body. The blog format likewise generates chaos, restitution and quest narrative structures in the recording of my continuing experiences.

27 Bogs enable people an outlet, and illness narrative blogs which focus on the articulation of the experience of illness in order to understand it better and/ or provide support to others, have emerged as an important subgroup in the blogosphere. These online spaces hold significance for life writing as they allow suffers (or recovers) a way to recover a sense of agency while transforming the private into public (McCosker). Power imbalances and social constructions are de- and reconstructed within these narratives. Patients become the experts online in a massive power shift and people who never recover from their illness or who eventually die as a result receive as much agency as those fully realising the restitution narrative. Although blogging was not an option available to me in 1997, based on my short and sometimes, several times a day journal entries, I imagine I would have used it if it were. I use blogs now as a way to navigate my life and experiences within and outside my research and writing in critical disability studies.

28 For Rosemary Garland-Thompson conventional narrative genres usually conform to an image of bodily stability and perpetuate cultural fantasies of loss and relentless cure seeking rather than present stories “possible because of rather than in spite of disability” (114). She argues that by presenting disability within the context of community in particular, disability can structure a positive story. Illness narrative blogs as they are firmly embedded within community achieve Garland-Thompson’s vision while also allowing for the narrative structures examined earlier in this article. The potential for each of the three narrative structures to be present at any one time within a blog generates different narrative models within illness narrative.

29 The cultural implications of the intersection between the social model of disability and disability and illness blogging can be seen in the way they “move beyond the medical versus social divide of disability” (Goggin and Noonan 165). My blog from 2006 compared to my musings about the social model of disability in 2004 demonstrate that while I ascribe to the social model of disability, my illness narrative is continually unfolding, impacting on my personal identity.

30 Through a focus on the individual, illness narratives have been accused of medicalising the experience of disability by perpetuating damaging stereotypes (Barnes 23). The social model must also respond to the stereotypical aspects of life, disability and illness (Waine; Ellis, “Aww Factor”). Tom Shakespeare draws on these critiques to argue that the social model must engage with impairment because it is a “central and structuring part of the experience [of disability].” Impairment is not neutral and while it does lead to disadvantage it also “lead[s] to opportunities: for example, to experience the world in a different way” (43):

I went back to University the year after my stroke to study film and media and in my final unit two years later I stood up at the beginning of the semester and pitched a film about my having had a stroke a few years before. Most of my class mates had no idea, I had successfully passed. My class voted to make this film and I began my process of “coming out” by talking about what I had experienced rather than silencing myself. My passing had deprived people of experiencing the diversity of society although it took me a while to embrace my illness and to realize illness autobiography and honour in disease are possible because of other marginalized groups taking pride in their stigmatized identities. (Ellis, “I Premiered My First Film in an Inaccessible Cinema” 9 August 2009)

31 Despite the proliferation of ill bodies in Western mass media, illness makes us uncomfortable. Illness and people who are ill are stigmatized and used to make the rest of society feel less tenuous about their own body stability. This stigma is perpetuated via mainstream media through the saturation of restitution narratives and the silencing of chaos and the idea that quest establishes a different way of being well. Goffman distinguishes between the *normals* and those who possess a stigma and argues that those who have stigmas such as physical deformities are discriminated against by the normals because “we believe the person with the stigma is not quite human” (73). Although Goffman recognises that an ideology is created in regard to stigma to explain inferiority and rationalise fears about the stigmatised group, he places the stigma within the body.

32 Definitions of illness operate on an ideological level through stigma, and the hegemony of ‘health’ is maintained as long as illness is individualised. Illness is not just there; it is constructed by the boundaries of normality. The most popular illness narratives project a cultural narrative of loss and cure seeking—our society encourages narratives that have happy endings. For Susan Sontag, this is because everyone holds membership within both the world of the sick and that of the well and we rely on the promise of medicine to cure all diseases (1). New identities, that acutely remind individuals of their difference, are resisted and stigmatised by wider society.

33 When I was invited to give a client’s perspective on experiencing neurological disability to a group of physiotherapists completing a Graduate Diploma in Neurological

Rehabilitation at the University of Western Australia, I decided to share several of the journal entries discussed throughout this paper, while reflecting on the way society encourages certain types of stories while discouraging others in order to reinforce socially constructed power imbalances:

My brief was broad, I could discuss whatever I wanted to; however, as I was invited due to my personal experiences, success and knowledge, I felt some pressure to tell an 'inspirational' story. I decided instead to talk about how I have told my 'illness narrative' and how this can be used in stroke recovery, particularly in relation to negotiating a changing identity. What an interesting experience! I titled my piece "Testimony: Illness and narrative" and used excerpts from my journal to highlight the differing narrative structures a person adopts when writing through trauma. The students who were largely practicing physiotherapists had trouble relating to me as a person with knowledge and attempted to turn me into a patient again, offering me advice on my walking and pointing out the way my movement changed when I revisited particularly traumatic times in my illness and recovery. This was despite my telling them that I found it difficult to read some particularly chaotic and depressing journal entries. They wanted the power, but I refused to give it up. Their attempts to put me in that position of patient again made me realize the importance of telling my own story all over again. (Unpublished Journal 17 August 2006)

Retelling my illness narrative in this way from the perspective of someone who had recovered but remained marked by their illness was difficult for the students to comprehend, and they encouraged me to adopt the restitution narrative, to socially and medically shape my experience once again; to treat me as a body to be observed. My cultural and literary interpretations of my own experiences left them wanting as they continued to medicalise me and others like me.

Conclusion

34 Prominent sociologist C. Wright Mills maintains that admirable scholarly thinkers draw on their life in their intellectual work (195-96). I have attempted to do this throughout this paper in order to foreground the importance of narrative knowledge within both medical knowledge and critical disability activism.

35 Taking health for granted looms large in our culture, "one of our most tenacious cultural fantasies is a belief in body stability" (Garland-Thompson 114). When illness does occur we relentlessly strive for a happy ending, and the most popular narratives retell a story of loss and cure-seeking. Arguably, the act of writing this article could be seen as a (re)telling of my restitution narrative; however, the inclusion of chaos aspects disrupts the culturally shaped framework of illness and recovery.

36 The narrative of recovery invariably includes aspects of grief and yearning for the past. The three illness narrative types I have discussed in this article are not separate entities in the search for an essential self. They are postmodern stages through which one passes and returns. There is power in sharing, and using writing as a means to work through pain invites creativity and innovation (Jones and Brabazon). While this article has predominantly focused on older forms of media, new media, such as blogs and virtual reality are providing people recovering from serious illness the chance to use narrative as a way to reflect on their recovery (Pajtas 13).

37 As a process of recovery, illness narratives invariably incorporate the chaos, restitution and quest structures. These narrative types display the relationship between narrative and culture, and emphasise the complexity of illness (Thomas-MacLean 1648). Narrative is vital, as the ill persons work out their changing identity and position in the world of health, continuing when they are no longer ill, but remain marked by their experience:

My interest in disability is largely due to my own experience with disability. Following a stroke, I have for the last eleven years lived with weakness and spasticity in the left side of my body and epilepsy. [Eight years ago] I made a documentary about my rehabilitation from stroke. During this exercise I began to notice that many able-bodied people who had not had similar experiences to my own were “reassuring” me that I looked and seemed “normal.” (Disabling Diversity 18 May 2008)

Disability and illness are not straightforward and warrant further investigation. Writing this paper has allowed me to think reflexively on my own illness and how it continues to affect my life, including my ongoing research and writing.

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Lauren Slater's *Lying*: Metaphorical Memoir and Pathological Pathography

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Abstract:

As public awareness of antidepressant medication surged in the 1990s, Lauren Slater's *Prozac Diary* became the quintessential auto-pathography, documenting her life with major depression and her dramatic "cure" with the wonder-drug Prozac. However, Slater's pronounced ambivalence about the drug's side effects and her treatment was largely ignored by a culture swept up by Prozac enthusiasm. Slater's more recent "metaphorical memoir," *Lying*, on the other hand, is not so easily appropriated. A parody of the illness narrative, a pathological pathography, *Lying* is the dark sister text of *Prozac Diary* – Slater's subversion of the autobiographical conventions and imperatives of the genre. Slater, who is both a psychologist and a patient, writes in the antipsychiatric tradition of David Rosenhan's "On Being Sane in Insane Places," the infamous 1973 study in which sane "pseudopatients" were incorrectly diagnosed with mental illnesses after feigning symptoms. By becoming a patient himself, Rosenhan called into question the seemingly discrete categories of sane and insane and revealed the structuring power of psychiatric labels. In a similar fashion, *Lying*, an autobiography about epilepsy, challenges and defies readers' expectations for truth and transparency in memoir and underscores the central role of the patient's story and the metaphorical nature of illness itself. *Lying* is a literary form of hysteria, a conversion evoking the complicated past of women, mental illness, and the authenticity of psychiatric diagnoses.

1 As public awareness of antidepressant medication surged in the 1990s, Lauren Slater's *Prozac Diary* became the quintessential auto-pathography, documenting her life with major depression and her dramatic "cure" with the wonder-drug Prozac. However, Slater's pronounced ambivalence about the drug's side effects and her treatment was largely ignored by a culture swept up by Prozac enthusiasm. Slater's more recent "metaphorical memoir," *Lying*, on the other hand, is not so easily appropriated. A parody of the illness narrative, a pathological pathography, *Lying* is the dark sister text of *Prozac Diary*; *Lying* is Slater's subversion of the autobiographical conventions and imperatives of the genre.

2 Yet such subversions are not widely appreciated. As the controversy over Jim Frey's *A Million Little Pieces* illustrated,¹ many readers expect the truth from memoirs, even if those memoirs are written by recovering drug addicts like Frey or psychiatric patients like Slater.

¹ Frey's "memoir," *A Million Little Pieces*, a recovery narrative about his drug and alcohol addiction, was an Oprah's Book Club selection, much increasing the book's already phenomenal sales. However, as reported by The Smoking Gun.com, parts of Frey's memoir were only loosely based on the truth, much embellished, or at worst, invented. For example, Frey spent only a few hours in jail, not the three months that he writes about so extensively ("A Million Little Lies"). Oprah eventually dropped her endorsement of the book, and in response to accusations of fraudulently marketing fiction as memoir, Frey's publisher, Random House, eventually offered purchasers refunds.

Slater's first memoir, *Prozac Diary*, was ostensibly just what it purported to be: a diary, an honest and truthful account of her experience with depression and of her treatment with Prozac. The promotional blurbs on the paperback cover of *Prozac Diary* emphasize this selling point: "Prozac's most honest narrator yet," says *Elle* magazine. "Brutally honest and brave," says *Entertainment Weekly*. Slater's next memoir, *Lying*, is quite the opposite: A "postmodern book that challenges our understanding of truth," says the *San Francisco Chronicle*. "Tricky," says *The Washington Post*.

3 Slater's project in *Lying*, I will argue, is more than simply an exercise in pushing the boundaries of the memoir genre, and her work in general raises issues that are central to the study of medical humanities, disability studies, and feminist critiques of psychiatry. Slater, who is both a psychologist and a patient, writes in the antipsychiatric tradition of David L. Rosenhan's "On Being Sane in Insane Places," the infamous 1973 study in which sane "pseudopatients" were incorrectly diagnosed with mental illnesses after feigning symptoms. By becoming a patient himself, Rosenhan called into question the supposedly discrete categories of sane and insane and revealed the structuring power of psychiatric labels. In a similar fashion, *Lying*, an autobiography seemingly about epilepsy, challenges and defies readers' expectations for truth and transparency in memoir, and underscores the key role of the patient's story in the clinical encounter and the metaphorical nature of illness itself. *Lying* is a literary form of hysteria, a conversion evoking the complicated past of women, mental illness, and the authenticity of psychiatric diagnoses.

Rosenhan Revisited

4 In 2004, Slater published *Opening Skinner's Box: Great Psychological Experiments of the Twentieth Century*, a book designed to translate historically significant work in psychology for a mass-market readership. This project was a natural next step for Slater, a writer with deep personal and professional connections to mental health issues. Her first book, *Welcome to My Country: A Therapist's Memoir of Madness* (1996), was a series of case studies/stories and drew upon her experience as a therapist and her interactions with her mentally ill patients. Her second book, *Prozac Diary* (1998), focused on her own experience with major depression, including her successful treatment with Prozac, which in turn had made her graduate work in psychology at Harvard possible. Slater is, furthermore, a prolific free-lance writer: she has contributed pieces to *National Geographic*, *New York Magazine*, and even popular women's publications such as *Self* and *Elle*. Her essay on the unconventional plastic surgeon Joe Rosen, "Dr. Daedalus," which was originally a cover story

for *Harpers*, was included in *Best American Science Writing* (2003). Considering her talents and her background, a book about past research in psychology would seem the perfect subject for Slater. In the introduction to *Opening Skinner's Box*, Slater traces the source of this book back to her graduate education in psychology:

I [...] read the classic psychological experiments [...] in academic journals, mostly, replete with quantified data and black-bar graphs—and it seemed somewhat sad to me. It seemed sad that these insightful and dramatic stories were reduced to the flatness that characterizes most scientific reports, and had therefore utterly failed to capture what only real narrative can—theme, desire, plot, history—this is what we are. The experiments described in this book, and many others, deserve to be not only reported on as research, but also celebrated as story, which is what I have here tried to do. (2-3)

Slater's celebration of story and dramatization of science, however, proved to be a difficult and controversial endeavor.

5 *Opening Skinner's Box* drew almost immediate criticisms. Interview subjects complained of being misquoted or misrepresented; reviewers complained of factual errors and sloppy research (see Lee). Even the title of the book contained a controversy. Slater opens with a chapter on B. F. Skinner, the behaviorist famous for his theory of positive reinforcement, and Slater's version of the "baby in a box" urban myth—a cruel tale of how Skinner raised his daughter Deborah in an experimental box, without the comforts of the crib, and the daughter's resulting madness and suicide. Though Slater claims to have searched for Deborah, she never succeeded in contacting her, and Slater depicts her as "missing" in the conclusion of the book and muses about her mental health: "Is she dented or damaged in some way? I don't know" (250). As Slater would learn later, Deborah Skinner Buzan is alive and well, and not at all pleased with Slater's book and the resurrection of old and arguably mean-spirited gossip about her beloved father's parenting skills: "I am not crazy or dead, but I'm very angry," she writes (7). Slater, some would argue, misled her readers by repeating, rather than putting to rest, unsubstantiated rumors about Deborah's supposed childhood abuse and mental illness. In the words of one critic, Slater created "a bogus miasma of mystery around Deborah's fate" (Miller 31).

6 The controversy over the Skinner chapter, though heated and litigious, pales in comparison to the debate engendered by Slater's chapter on David L. Rosenhan's study, "On Being Sane in Insane Places." In Rosenhan's original study, eight volunteers (including Rosenhan himself) made appointments at the admissions offices of various psychiatric hospitals where they complained about hearing voices that said "empty," "hollow," and "thud." This was the only symptom that they feigned, and after gaining admission to the hospital (all were admitted in every instance), each "pseudopatient ceased

simulating *any* symptoms of abnormality” (Rosenhan 251; emphasis in original). Rosenhan’s “pseudopatients” stayed in the hospital for an average of 19 days, with length of stays ranging from 7 to 52 days (252). When they were released, they were released because they were judged to be in “remission” of a mental illness. Despite being “people who do not have, and have never suffered, symptoms of serious psychiatric disorders,” their “sanity” was never detected by doctors or hospital staff (251). Rosenhan began this study with the question, “do the salient characteristics that lead to [psychiatric] diagnoses reside in the patients themselves or in the environments and contexts in which observers find them?” (251). His results suggested that “psychiatric diagnosis betrays little about the patient but much about the environment in which an observer finds him” (251). Furthermore, Rosenhan concluded, “any diagnostic process that lends itself so readily to massive errors of this sort cannot be a very reliable one” (252). Rosenhan’s experiment is well-known, often cited, and has helped to fuel skepticism about the reliability and accuracy of psychiatric diagnoses. As one of Rosenhan’s most vocal critics, Robert L. Spitzer, ruefully noted in 1975, “this single study is probably better known to the lay public than any other study in the area of psychiatry in the last decade” (“More on Pseudoscience” 459).

7 Slater not only echoes Rosenhan’s critique of psychiatry by retelling it; she also reinforces the conclusions of his original study by repeating the experiment itself and reporting similar results. Slater stops showering for five days, visits a psychiatric emergency room, and complains of hearing the word “thud.” Slater writes:

It’s a little fun, going into ERs and playing this game, so over the next eight days I do it eight more times, nearly the number of admissions Rosenhan arranged. Each time, of course, I am denied admission—I deny I am a threat and I assure people I am able to do my work and take care of my child—but strangely enough, most times I am given a diagnosis of depression with psychotic features [...]. I am prescribed a total of twenty-five antipsychotics and sixty antidepressants. (88-89)

Slater concludes that “the zeal to prescribe drives diagnosis in our day, much like the zeal to pathologize drove diagnosis in Rosenhan’s day” (90).

8 The number of medications that Slater was prescribed during her experiment was truly shocking: an average of about nine different medications per emergency room visit. In her book, Slater recounts her experiment to Robert L. Spitzer, the very same psychiatrist who was Rosenhan’s critic in the 1970s and who led the American Psychiatric Association task force that created the *DSM-III* in 1980.² Spitzer was initially both disappointed and a little

² *The Diagnostic and Statistical Manual of Mental Disorders (DSM)* is the official American Psychiatric Association reference manual, listing all mental disorders and the criteria by which these disorders are diagnosed; it is the diagnostic bible of psychiatry.

defensive when he learned of her results: “‘You have an attitude,’ he tells me, ‘like Rosenhan did. You went in with a bias and you found what you were looking for’” (*Opening Skinner’s Box* 90). After the book’s publication, Spitzer challenged Slater’s findings in a more public, systematic way, by responding to her experiment in a peer-reviewed professional journal. Unlike his previous responses to Rosenhan, which were thoughtful and complex essays that painstakingly critiqued the logic of the original study’s methods, interpretation of the data, and conclusions,³ Spitzer took a different approach to Slater’s experiment: he repeated it. Working together with two colleagues, he created a case study vignette based on Slater’s own description of her emergency room presentation and a series of questions about diagnosing, treating, and prescribing medication which he then distributed to emergency room psychiatrists. Spitzer’s results differed in significant ways from Slater’s results. Of the 73 doctors who responded to Spitzer’s survey, only 6% diagnosed psychotic depression and 34% prescribed antipsychotic medication (Spitzer et al., “Rosenhan Revisited” 737). While Slater reported an average of 6 different prescribed antidepressants per visit in her experiment, none of the doctors in Spitzer’s study prescribed any antidepressants. While acknowledging the distinct differences between Slater’s first-hand experiment and the written survey based on her performance of symptoms, “it strains credulity,” Spitzer and his colleagues wrote, “to contend that Slater’s physical appearance alone was sufficient to account for the discrepancy [in final data] across studies” (738). Slater, furthermore, refused to share “any documentation such as case records (with identification deleted) or hospital bills or to explain puzzling details about her reported experiences, such as how she was prescribed 85 medications on only nine occasions” (738). “Our failure to corroborate Slater’s findings, conjoined with her unwillingness to supply us with any objective documentation, raise troubling questions about the credibility of her study’s findings,” they concluded (738). In other words, they implied, Slater is lying.

9 Spitzer and his colleagues published their findings in *The Journal of Nervous and Mental Disease* and Slater was invited to respond. The exchange that followed was not the typical academic difference of opinion. Slater’s tone was mocking and irreverent, and she depicted her critics as foolish for even thinking about engaging with her in this venue:

I am a bit at a loss as to how to respond to the “critique” by Spitzer et al. of my Rosenhan “study” because as a trade book writer, I never did such a study; it simply does not exist. This puts me in an awkward position, but probably not as awkward a position as it puts you—the editors and peer reviewers—for accepting for publication

³ Spitzer, “On Pseudoscience in Science” and “More on Pseudoscience in Science.”

before reading the text (my book) toward which the rebuttal is aimed. I'm sure this is not common practice. (743)

"I write for fashion magazines almost exclusively," claimed Slater, and the personal and eccentric content of her prose should have signaled to them that her writing lies beyond the scope of this form of academic critique:

That Spitzer et al. have chosen to label my work as a study is a silly and troubling mischaracterization; it is a manipulative mischaracterization as well, for of course such esteemed men must know that pet raccoons, dog dandruff, dahlias, and pooper scoopers firmly locate a work in something altogether outside of academia. ("Reply to Spitzer" 743)

These "esteemed men" should know better than to squander time and resources on such a silly attack on her: "I, for one, do not want my tax dollars being spent by men on such poorly conceived and misleading projects" (744). Although she refers to her re-enactment of Rosenhan numerous times as an "experiment" in *Opening Skinner's Box*, she claims here that her "use of the word 'experiment' is of course vernacular, as in 'honey, let's experiment with this recipe tonight'" (743). She's just a woman writing for fashion magazines and playing around in the kitchen; Spitzer et al. are humorless male bureaucratic scientists who take everything too seriously.

10 Slater's central defense is to challenge the language that Spitzer depends upon and to strategically reestablish the disciplinary boundaries between the vernacular and the scientific, boundaries that she has previously worked hard to transgress or bridge in her work: Spitzer logically cannot critique a "nonstudy" or a "phantom study." In addition to rejecting the terms of his critique, she also parodies the scientific method Spitzer deploys by mocking the conventions of experimental research:

Because I am neither an academic nor do I have any university or organizational affiliation, I lacked access to an Institutional Review Board to approve my inquiry, its methods, and underlying ethics. I was able, however, to cobble together my own IRB, which consisted of Dr. McFarland, our hamster's vet; Yassir Mizra, the owner of the wonderful neighborhood café Sound Bites; Ally Hines, member of our PTA; Andreas Lopez, the used car salesman who sold me the \$4000 Subaru with 71,000 miles on it (all-wheel drive); my neighbor, Mr. Smith, who is on parole; and Lorna, our school crossing guard. (743)

Although the primary purpose of such a passage may be to entertain us, at Spitzer's expense of course, it is worth noting that this comic deflection begins with an acknowledgement of the power relations structuring this debate. Despite her successes as a writer and her graduate degree in psychology, Slater is an outsider, without academic affiliation and without

authority. She is at a rhetorical disadvantage here, and her response can be read as a desperate attempt to alter the terms of the debate.⁴

11 Slater's reply left her critics in the strange position of having to defend themselves for taking her seriously, for crossing the science/culture divide. "It is a value judgment as to whether possibly fabricated data in a popular press book should be the basis of a report in the scientific literature," Mark Zimmerman, the reviewer for *The Journal of Nervous and Mental Disease*, writes (741). Spitzer and his colleagues initially defended their report by noting the potential influence of Slater's work:

Some readers may harbor the view that our findings are much ado about nothing. After all, they might contend, Slater's results were not peer-reviewed and can safely be ignored by the scientific community. In our view, this response would be misguided. Because Slater's book was undoubtedly read by thousands of individuals in the general public, it is probably more likely to shape the laypersons' impressions of diagnostic and prescription practices of psychiatrists than are peer-reviewed publications. Mental health researchers ignore popular perceptions of psychiatry and psychology at their peril [...] and must remain vigilant about correcting potential distortions and misrepresentations of scientific findings that are promulgated to the general public. ("Rosenhan Revisited" 738)

This conversation exists at the uneasy intersection of the concerns of "scientific community" and the "general public," which is in part why it is such a difficult and heated exchange. Slater has emphasized the cultural differences between the language and practices of the scientific community and those of the laity: "honey, let's experiment with this recipe." However, as Zimmerman notes, the divide between science and popular culture is not so pronounced as to be unbridgeable, and Slater clearly has knowledge of both realms: "It is disingenuous for Slater to now try to hide behind a cloak of a nonscientific writing style. It is clear that she understood the impact, importance, and implications of Rosenhan's study and her own study" (Zimmerman 741). It is perhaps disingenuous of Slater to respond this way, but it is also in keeping with her past work to be deliberately obscure, and to purposefully raise more questions than she will answer. In "A Response to a Nonresponse to Criticisms of a Nonstudy: One Humorous and One Serious Rejoinder to Slater," Spitzer and his colleagues eventually recognize the futility of engaging with Slater on their terms: in the end, they are quoting comedian Gilda Radner ("Never mind!") and are just as sarcastic as Slater herself. They are left with lingering doubts:

⁴Slater's status as a former psychiatric patient adds another layer that might undermine her authority to speak. As Catherine Prendergast writes, "to be disabled mentally is to be disabled rhetorically" (57), and Slater herself acknowledges that as a former mental patient she would not qualify as a pseudopatient under Rosenhan's original criteria. Slater's rhetorical position is never explicitly pathologized in this dispute, however.

Slater's response suggests another question: did she even perform her study in the first place? She does not provide readers with evidence that it ever took place. By "nonstudy," does she mean only that her hospital observations were unsystematic or unscientific? Or does she also mean that the events she described were fictional? (Lilienfeld 745)

It is perhaps fitting that this exchange ends with questions like these, which involve the fuzzy boundaries of truth and imagination in creative nonfiction and the unique blend of medical fact and personal observation that is typical in much of Slater's writing.

12 The relationship between fact and fiction in psychiatry is of particular interest to Slater, and Rosenhan's experiment lends itself to examining possible manipulations in the power structure of clinical encounters. Rosenhan's original experiment was, after all, based on fictional symptoms: the auditory hallucinations that the pseudopatients feigned in their admission interviews. Rosenhan's experiment began with a strategic violation of the contract of the clinical encounter between doctor and patient, in which the patient presents symptoms to the doctor who in turn reads those symptoms in order to diagnose and treat. In his experiment, which is based on an initial misreading—a failure to distinguish malingering (fiction) from a truly experienced symptom (fact) during admissions—staff and doctors continued to misread some behaviors of the pseudopatients as pathological during their hospitalization. Although Rosenhan's primary objective might have been to cast doubt on the validity of psychiatric diagnoses, the experiment also illustrates just how dynamic the clinical encounter can be: patients have potential power over how they present (they can manipulate their readers/doctors), and doctors themselves can become test subjects (the objects of examination).

Lauren Slater's *Lying*

13 Lauren Slater's memoir of growing up with epilepsy, *Lying: A Metaphorical Memoir*, similarly foregrounds and manipulates the expectations of the reader in order to transgress the conventions of the illness narrative. She writes:

[...] despite the huge proliferation of authoritative illness memoirs in recent years, memoirs that talk about people's personal experiences with Tourette's and postpartum depression and manic depression, memoirs that are often rooted in the latest scientific "evidence," something is amiss. For me, the authority is illusory, the etiologies constructed. When all is said and done, there is only one kind of illness memoir I can see to write, and that's a slippery, playful, impish exasperating text, shaped, if it could be, like a question mark. (*Lying* 221)

The text itself begins with a fake introduction written by a fictional philosophy professor.⁵ Chapter one consists of two words: “I exaggerate” (3).

14 While Slater’s text is ostensibly about epilepsy, she makes it clear from the very beginning that her account is not the typical illness narrative, and her epilepsy is a literary, not a literal, illness:

I have epilepsy. Or I feel I have epilepsy. Or I wish I had epilepsy, so I could find a way of explaining the dirty, spastic glittering place I had in my mother’s heart. Epilepsy is a fascinating disease because some epileptics are liars, exaggerators, makers of myths and high-flying stories. [...] when I opened my mouth [...] all my words seemed colored, and I don’t know where this is my mother or where this is my illness, or whether, like her, I am just confusing fact with fiction, and there is no epilepsy, just a clenched metaphor, a way of telling you what I have to tell you: my tale. (5-6)

Slater’s strategy in *Lying* is problematic on several levels. Traditionally, a memoir writer has an implicit contract with her readers to base her story in fact, not fiction or metaphor, and some readers are unwilling to permit Slater’s sweeping alterations in the terms of that contract.

15 A quite different objection to Slater’s conceit comes from the field of disability studies. As G. Thomas Couser writes: “[...] the ethical crux of *Lying* is not that Slater may be lying about having epilepsy, but that in exercising prose license she commits herself to an essentializing and mystifying characterization of a still stigmatic disability” (141). In other words, Slater’s memoir stigmatizes real people who live with epilepsy. Margaret Price voices similar objections:

[...] in the choice to appropriate another disability to stand in metaphorically for her own, Slater is on risky ground. I do not wish to defend her choice, which I find problematic for a variety of reasons. For one thing, it risks playing into the accusations of “malinger” so often leveled at disabled persons—especially those of us who have no objective evidence to offer, but only reports of what is happening inside our minds. And yet, perhaps in its very shamelessness lies its value. With this lurid gesture of untruth, the narrator of *Lying* refuses to become the exposed, confessing narrator of conventional disability autobiography. (20)

The politics of personal representation are vital to disability studies, a civil rights movement characterized by the slogan “Nothing about us without us.” In this context, Slater’s manipulation of autobiography is dangerous, but also potentially liberating. *Lying* complicates a genre that has been too easily packaged and consumed in the recent past.

⁵ For a description of reviewers’ attempts to track down the fictional Professor Hayward Krieger, see Richard Ingram’s “Life Plagiarizing Illness: Lauren Slater’s *Lying*.”

16 Price, an astute reader of Slater, describes *Lying* as “counter-diagnosis”: “In counter-diagnosis, the autobiographical narrator uses language [...] to subvert the diagnostic urge to ‘explain’ a disabled mind” (17). A counter-diagnosis is oppositional, yet also feeds off of the power of diagnosis: Slater’s *Lying* “neither embrace[s] diagnosis as truth nor reject[s] it as useless: instead [...] [it draws] power from the shape-shifting nature of counter-diagnosis, accepting, rejecting, mimicking, and contesting the diagnostic urge in various ways. Counter-diagnosis is an oxymoronic form” (17). As a counter-diagnosis, *Lying* purposefully manipulates readers’ desires to diagnose the problem that is Lauren Slater.

17 It would be a mistake, however, to read “epilepsy” as the counter-diagnosis or metaphor that Slater offers in place of or as a substitute for “depression.” *Lying* cannot be reduced to a mental illness memoir dressed up as an epilepsy memoir: Slater’s story is a complex hysterical conversion that translates the experiences of her childhood in indirect ways. “Epilepsy,” if it can be pinned to anything specific in this text, is a metaphoric vehicle or conceit that describes Slater’s relationship to her mother, not a specific medical condition or disorder. Slater’s mother is a central if spectral figure in the text: “She was a woman of grand gestures and high standards and she rarely spoke the truth. She told me she was a Holocaust survivor, a hot-air balloonist, a personal friend of Golda Meir. From my mother I learned that the truth is bendable, that what you wish is every bit as real as what you are” (5).

18 In *Lying*, Slater’s epilepsy is engendered by her mother: first grand mal seizure occurs on New Year’s Eve in Barbados when she is ten. Her mother has just embarrassed herself by creating a scene in the hotel restaurant: loudly making disparaging comments about the hotel piano player: “He doesn’t have much Mozart in him”; “Such heavy hands”; “You’re a sweet man with many sweet things in you, but with no thunder. A man should have thunder” (17). When the pianist calls her bluff and asks her to play, she takes the bench, places her hands carefully, and freezes. Although she owns her own engraved Steinway and fancies herself a great pianist, Slater’s mother knows only one song, “Three Blind Mice.” She excuses herself as the crowd watches. Later that night, Slater has her first seizure: “you grit your teeth, you clench, a spastic look crawls across your face, your legs thrash like a funky machine, you hit hard and spew, you grind your teeth with such a force you might wake up with a mouth full of molar dust, tooth ash, the residue of words you’ve never spoken, but should have” (19). Slater’s seizure is the awful show-stopping performance that her mother avoids: “Sometimes, after I’d woken up from a seizure, I felt so sorry for her, I felt it was really she who’d had the seizure, she whose muscles really ached, and over and over again in my mind, I brought my mother milk” (37). And later, the seizures seem like a form of possession in which the

daughter is the medium for the mother's repressed energy: "all her energy was really deadness; not me. I was a girl in motion. I was wrong and dark and full of smells. When a seizure rolled through me, it didn't feel like mine; it felt like hers—her ramrod body sweetening into spasm" (24).

19 Although Slater eventually comes to embrace her own individual identity as an epileptic, this illness is always linked to her relationship with her mother: "I was not a girl at all, but a marionette, and some huge hand—my mother's hand?—held me up, and for a reason I absolutely could not predict, that hand might let the strings go slack" (31). So Slater begins to take control of her illness by purposefully having seizures in the emergency rooms of various Boston hospitals: she wakes up to hands reaching out to her, providing her with the nurturing touch and care that her mother cannot or will not give her. These actions complicate Slater's story even further:

Now we get to a little hoary truth in this tricky tale. The summer I was thirteen I developed Munchausen's, on top of my epilepsy, or—and you must consider this—perhaps Munchausen's is all I ever had. Perhaps I was, and still am, a pretender, a person who creates illnesses because she needs time, attention, touch, because she knows no other way of telling her life's tale. Munchausen's is a fascinating psychiatric disorder, its sufferers makers of myths that are still somehow true, the illness a conduit to convey real pain. (88)

Slater poses the possibility that her illness is both neurological and psychogenic, both physical and hysterical. Or—since Munchausen's is a real psychological disorder involving physical illnesses that are not present—a real metaphorical illness. Slater would like to have it both ways or, rather, as many ways as possible. She writes, "[t]he neural mechanism that undergirds the lie is the same neural mechanism that help us make narrative. Thus, all stories, even those journalists swear up and down are 'true,' are at least physiologically linked to deception" (*Lying* 164). Lying and narrative, therefore, are biologically indistinguishable both in the body and in Slater's text; this is a clever scientific explanation with dubious value in this context, if fact finding is your mission. "The counter-diagnostic story," Price writes, "does not merely parallel or replace the conventional diagnostic story: it ruins it altogether, attacks its foundations, queers it" (17).

20 In the professional diagnostic literature, such as the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* and the World Health Organization's *International Statistical Classification of Diseases* (ICD), Munchausen's is part of a class of "factitious" disorders, a term that is especially evocative in the context of Slater's *Lying*. In a chapter entitled, "How to Market This Book," which takes the form of a memo to her editor at Random House, Slater discusses the generic classification of her book:

We have to call it fiction or we have to call it fact, because there's no bookstore term for something in between, gray matter. If you called it faction, you would confuse the bookstore people, they wouldn't know where to put the product, and it would wind up in the back alley or a tin trash can with ants and other vermin. You would lose a lot of money. (159-60)

Both “factitious” and “faction” are portmanteau words that describe a patient's/writer's manipulation of the factual and the fictional, and each gains its respective meaning from, in the case of “factitious,” the dynamics of the clinical encounter and from, in the case of “faction,” the generic conventions governing the memoir writer's contract with the reader. There is a sense in which all illness narratives are forms of a clinical encounter, in which the writer is the patient who presents and performs her symptoms for the reader. If the reader's approach to the text is heavily structured by the diagnostic gaze, then the narrative can become the equivalent of a case study, read primarily to provide information about an illness. It is this type of reading and objectification that Slater attempts to resist. To read *Lying* “literally, like it was just one more true account of yet another illness” is a mistake: “If you read it that way, I will feel I have failed” (161-62). Slater insists that the book is properly a memoir: “My *memoir*, please. Sell it as nonfiction, please” (165). Whether Slater's negotiation of the demands of the marketplace is successful is arguable, and her strategic use of epilepsy and malingering is certainly risky and problematic. Nevertheless, reading *Lying* ultimately forces us to examine the multiple ways in which our experiences and ideas are pathologized and categorized, the ways in which we are complicit in that process, and the limited terms of our possible rebellion.

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A Balancing Act: How Women with a Hidden Disability Perform Femininity

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Abstract:

The word “disability” carries strong cultural and social symbolic meaning. The impact of these meanings is entrenched in the storied experiences of either embracing or repelling “disability” as a self-characteristic. Persons with a “hidden disability,” one that is unapparent to the unknowing observer, make daily decisions about when, where, why, and how to disclose and adopt the disability identity or to “pass” and give society the impression of able-bodiedness. These decisions are heavily influenced by the bodily and social performance expectations of a given gender. Such gender expectations have reverberating effects on self-concept, relationships, and the way one interacts with the world. This study used a narrative research methodology to understand the identity processes of four women ranging in age from 21 to 46 years who have a hidden disability. Victoria has Juvenile Rheumatoid Arthritis; Angela has Epilepsy, Mary has Mitochondrial Myopathy, and Rosalina has Celiac Disease. In this essay, I also reflect on my own experiences as a woman with a hidden disability, Muscular Dystrophy. Through these personal, emotional, and insightful self-narratives, each woman relays the complexity of self-disclosure and disability identity.

All the world's a stage, And all the men and women merely players: They have their exits and their entrances; And one man in his time plays many parts. William Shakespeare, *As You Like It* (1600)

Introduction *Hidden Disability*

1 A “hidden disability” is one that is unapparent to outside observers except by disclosure or unusual circumstances. While persons with hidden disabilities are afforded a sense of anonymity, they must contend with different challenges, including learning strategic self-disclosure and impression management; when to disclose and make disability visible and when to “pass” and give society the impression of able-bodiedness. The choice, to be or not to be disabled, has important implications for the way we conceptualize disability, and the concept of identity as a whole. Gendered social expectations impact these decisions on a constant basis.

2 This paper uses a narrative research approach to understand women’s personal identification (or lack thereof) with being “disabled” and the impact of womanhood on this identity process. I will focus on the self-narratives of four women, ranging in age from 21 to 46 years, who have a hidden disability. Victoria has Juvenile Rheumatoid Arthritis; Angela has Epilepsy; Mary has Mitochondrial Myopathy, and Rosalina has Celiac Disease. In this essay, I also reflect on my own experiences as a woman with a hidden disability, Muscular Dystrophy. *Narrative Research Methodology*

3 Through a face-to-face two-hour tape-recorded guided conversation with Victoria, Angela, Mary, and Rosalina, I solicited the unfolding of each woman's "story" prompted by the question, "Tell me about what your life has been like living with (specific condition), from the beginning." Each woman had the opportunity to respond to the presentation of data, joining with me in the construction of the results, enabling a sense of 'co-ownership' of the research. In this process, the participants and I together embraced the discovery of the experience of hidden disability.

4 A narrative research methodology is used to present the results. Using *narrative construction*, I assemble the elements of a participant's descriptions into a single vivid narrative to draw the reader into the individual's lived experience as an alternative reality (Barone and Eisner; Polkinghorne). This data presentation is meant to enable 'empathetic witnessing' of a different kind of life to inspire a dialogue between the reader and the text, invoking an understanding of why and how a person acts as he or she does (Barone and Eisner; Coulter; Docherty and McColl).

5 While narrative construction is used to emphasize unique differences across cases, *analysis of narratives* is used to generalize to the overall experience of hidden disability. Analysis of narratives illuminates universal features of participants' stories, breaking the participants' overall narrative into paradigmatic categories, allowing for common themes to emerge across the collected stories (Polkinghorne). By reading the interview transcripts over and over, *key linkages*, common themes and ideas, emerged (Charmaz and Mitchell; Erikson). These key linkages were then grouped with others as part of an overarching concept, leading to the construction of categories of central significance (Erikson; Polkinghorne). This overall process, in effect, brings order and consistency to the data by classifying sections according to their commonalities (Polkinghorne).

Narrative Construction

6 Mary gripped her mug of tea in one hand, the stair railing in the other and eased her way down three small steps. She sunk into a lawn chair, its tattered material sinking with her weight. The sky was a mixture of pinks and oranges, as the sun slowly disappeared. A lone cactus stuck out of the ground, disrupting the flat horizon. It leaned slightly to the left, its arms extending upward as if ready to fight its impending doom brought on by men, materials, and machines.

7 Her mind shifted back to her day at work. It always took a cup of tea and deep breathing to relax her mind before night descended and it was time to fall asleep and start all

over again. The most unsettling aspect of waking up was not knowing whether her body would work the way she instructed it to, or if it would fail her when she least expects, embarrassing her in front of her coworkers. Today was a perfect example of that dreaded humiliation. As she recalled it, the rancid feeling in her stomach returned.

8 That afternoon, Mary had skipped lunch break. The constantly ringing phone had to be answered and insurance claims had to be dealt with. The day had seemed especially busy and if she let the calls go to voicemail, she knew she would be more overwhelmed later. Around four o'clock, her stomach growled an unhappy reminder that it missed a meal. She should have known better than to skip a meal in the first place, especially in the midst of a demanding day. By now, Mary knew that if her body didn't get the nutrition it needed when it needed it, it would rebel.

9 On her way to the kitchen, a young coworker stopped her to ask if she took care of a call he'd forwarded to her. She hadn't yet, but she didn't want to explain this to him, because she could feel *it* coming on. She knew she had to get to the kitchen, to the lunch sack waiting in the refrigerator. She threw a brisk answer at him as she moved. Oh no! She realized it right away ... her tongue hadn't quite formed the words properly and her words came out slurred. With a mocking, but intrigued look on his face, he followed behind her. Consciously Mary formed each word in her mind before verbalizing it. Slowly, meticulously, she made every effort to enunciate each syllable, hoping to make him think he had imagined it.

10 "You're slurring, Mary! Did you knock a few back over lunch?" His laughter bounced off the walls. Mary could feel her face burning with embarrassment. She tried to laugh with him, "I'm so tired, I can't even think or talk straight!" But, his arrogant eyes narrowed, seeing right through her forced laugh. Escape to the bathroom, she instructed herself, but her legs wobbled and she stumbled. Of all times for her leg weakness to kick in! This instigated more heckling, louder and more obnoxious, drawing the attention of several people she supervised. She felt her credibility slipping away. In a rush of emotion and defensiveness, she almost blurted 'it' out into the air like a quest for legitimacy. But the voice in her mind reminded her, '*Bathroom!*' and she escaped.

11 Now looking back on it, she felt thankful she hadn't reacted in emotion sharing with this insensitive coworker such a private aspect of her life. After years of doctors in long white coats peering over spectacles with clipboards in hand, transition questions from physical to emotional, concluding with a possible diagnosis of Depression and Somatization of symptoms, she had nearly given in to believing that it must be all in her head. Mary had gone years without the security of a label, despite countless blood draws, strength tests, and muscle

biopsies. When the diagnosis finally came, it was bittersweet. Mi-to-chon-dri-al My-o-path-y. The doctor sounded it out with a glint of pride as if coming up with a stickler for a spelling bee.

12 Mitochondrial Myopathy! A form of Muscular Dystrophy. These words on a piece of paper, in black and white, were proof that it was not all in her head. She felt like shouting from rooftops, “I have a name.” Her teachings in Judaism engrained in her the concept of Yahweh—if you can name it you own it. This is why the Jewish people tried to get God to give them His name. If they knew His name, they could control Him. And that’s why God responded, “No, my name is Yahweh, I am who I am.” Mary felt like because she could name her condition, she could own it and exert a little more control over it.

13 Gradually, however, control was slipping through her fingertips. Her move to the southwestern desert coincided with her body revealing her diagnosis more and more frequently without her permission. When it began affecting her work relationships, Mary sought out a new neurologist for answers. Armed with a thick file of paperwork, Mary explained, “It’s getting worse. I am slurring my speech, and I’ve never had such severe muscle cramping like I’ve had in the past year. My legs go numb all the way up to the thigh, every other day. I have to crawl around my apartment.”

14 Looking at her barely covered by a paper-thin cloth, the doctor said matter-of-factly, “Well,” looking down at the chart to find her name, “Mary. At least you’re not in a wheelchair.”

15 A breeze was picking up and Mary pulled her sweater closer, shuddering with exasperation at this memory. The chorus of howling coyotes rose with the darkness. But at least they had each other, Mary thought with jealousy. Last week, Mary had mustered up the courage to seek out the monthly support group run by the Muscular Dystrophy Association. She had felt excited, desperate even, for the possibility of meeting someone whom she can relate to, whom she can learn from, whom she can confide in and conspire with.

16 As soon as she walked into the room and saw several overbearing black electric wheelchairs and heard loud whirring machines, she’d concluded that she’d made a mistake. One man used his lips to move a stick which propelled his wheelchair towards her.

17 “Welcome,” she thought he said. “Come in.”

18 She pulled a folding chair over to this lopsided circle. “I’m Mary,” she introduced herself, “I have Mitochondrial Myopathy. I came tonight to meet other people with MD.”

19 They looked her up and down, appraising every curve of her body that implied muscle lay beneath, as if evidence of an outright lie. The man, speaking on behalf of the group repeated himself, “Well ... welcome.”

20 In the hour that followed, no one spoke about anything Mary could relate to. The group shared the challenges of feeding tubes, breathing tubes, IV needles, inaccessible buildings, and personal care attendants. They discussed their week, each person describing the experience of confronting and clashing with ableist stereotypes and oppressive attitudes. Mary looked around blankly. They were trying to get others to understand and recognize all the things they *can* do as people with disabilities. She was trying to get people believe that she had a disability and to recognize the things she could not do. During the bathroom break, Mary grabbed her cloth bag and made for the door.

21 The light of the moon reflected off her now empty mug. She gazed out over the vast emptiness. Alone, she thought. I’m alone in this one.

Analysis of Narratives

Feminized Disability Identity

22 The body is a symbolic and cultural bearer of value (Edwards and Imrie). It is a tool that communicates the junction of both gender and ability. Persons with a hidden disability differ from nondisabled persons because they are often intimately aware of their bodily performance (Corbin). Similarly, ‘doing gender’ is an unconscious process for most (Butler, *Gender Trouble*; “Gender as Performance”; Brickell). In the United States, as well as many other parts of the world, gender norms and expectations exist in all social situations, dictating how men and women are supposed to look, behave, and what they are supposed to be able to do: how they are supposed to perform (Butler, *Gender Trouble*; Wilson). The expectations for a gendered performance becomes ingrained in us from the moment we are wrapped in a pink or a blue blanket and cooed at that we are ‘pretty’ or ‘handsome.’ A masculine person should embody strength, rationality, self-reliance, determination, and perseverance (Robertson; Shuttleworth). Women, on the other hand, are expected to embody beauty, nurturance, dependence, compassion, and vulnerability.

Self-Concept and Disability

23 Goffman coined the term dramaturgy to describe the performance that two people engage in when interacting with each other. It is during this dramaturgical performance that an ‘actor’ manages the impression of the ‘audience’ (real or imaginary) by asserting and

emphasizing certain qualities and downplaying or hiding others, both verbally and nonverbally (Riessman). Humans seek to perform in ways that will promote a favorable impression of themselves (Brickell). The self-concept is consequently affected by what we do in our performance (Herek).

24 The self-concept is a person's self-perceptions formed through experience with and interpretations of one's environment (Bracken). The development of a self-concept is a continuous process, constantly changing to integrate experiences and feelings (Charmaz and Paterniti). A self-concept is negatively affected by shame (Matthews). Shame is a painful emotion involving the negative evaluation of the global self resulting from the perception that one's self or one's presentation to others has not met with one's personal expectations. At the core of shame there is the belief that oneself is bad, deficient, defective, inadequate, and unworthy (S. Taylor; Dickerson), which occurs in response to a discrepancy between one's actual self and one's ideal self, or when one fears being negatively evaluated by others (Bracken).

25 One is most vulnerable to shame when s/he is exposed as inadequate or defective, when feeling rejected or weak, when his/her situation is out of control, or when an uncontrollable and/or undesirable characteristic is made salient, for example, when a symptom of a hidden disability occurs publicly (Matthews; Dickerson). When this happens, the individual might respond with an overpowering desire escape the social situation or to hide to conceal the 'defective' self from social scrutiny (Dickerson).

26 Perceived skeptical attitudes and doubtful comments from members of the support system reinforce fears of a 'discreditable' self (Davis; Matthews). When a person has a disability that is not apparent, or when acute symptoms are present one day and few or none are present the next, members of his/her support system often unknowingly minimize the experience or give an impression that the condition is not believable. Many family members and friends openly question the reality and severity of the disability (Charmaz and Paterniti; Matthews). Mary explains her experience with this within her support circle: "I still get the same type of response from even family and friends. 'Ooh you don't look that bad.' 'You go hiking with me, you can't be that bad.'"

27 When interactions with authority figures regarding the disability are met with hostility and resistance, one might feel as though he or she is personally disliked because of the disability claim. Victoria explains feeling targeted and publicly humiliated when her requested accommodations were flat-out denied by a teacher that she perceived as spiteful:

I went through a remission at about age 12 or 13. My body developed, I grew, and I wasn't as small and skinny and sickly-looking as I had been before. Coming out of remission caused a lot of problems, I think, because I looked like everybody else. I wanted to look like everybody else. I wanted to put makeup on, and I wanted to do my hair. I liked to keep myself looking nice. But because I did that, I think the teachers looked at me like, "There's nothing wrong with you." The teachers were really mean to me. It started in middle school.

28 Health professionals react differently to people with hidden disabilities than to those with visible disabilities (Charmaz and Paterniti; Davis). Service providers might react with disbelief, lack of knowledge about how the disability presents itself, and overall lack of responsiveness, treatment planning, and service referral (Taylor and Eisele; R. Taylor). Mary describes her experience:

I feel guilt, because when I do tell someone about it, I feel like they don't believe me. I feel like, oh, it's not that bad. That's what doctors have told me. "Oh, it's not that bad. At least you're not in a wheelchair." ... I feel like I should have my lab results or my biopsy results with me and say "here, see, look, its right there." ... Even with doctors I feel like I need proof because I look too good ... I've gone through hell because of it ... Doctors looking at me like there's nothing wrong with me. ... I mean, I felt like saying to him, are you going to pay more attention to me and help me once I get into a wheelchair?

29 Even strangers express dissatisfaction with stares, frowns, silent disapproval, and outright verbal questioning when persons with hidden disabilities access special accommodations (S. Taylor). Persons with hidden disabilities then face the additional burden of explaining or proving to others why they need a particular service, which can, in itself, be a shame-producing experience (Matthews). Simply the fear of having to do so keeps Mary from accessing necessary accommodations:

I've never used (accommodations) even when I need to use them ... because I didn't know what to say to people. I even got the parking permit (application), and I was going to ask the doctor to fill it out, and I thought people are going to look at me and say, "She's not disabled. She's using somebody else's permit." I just never did it because I never wanted to deal with people saying anything to me. There's that 'different' again. I mean, that's my issue that I need to work on, but I'm getting this close to asking the doctor to fill it out. Because when I feel that bad, I would like to be able to park closer so I don't have to expend as much energy. I thought about it, and thought I wouldn't use it if I wasn't feeling bad, so I wouldn't feel guilty. Here I am saying, 'Oh no, I'm just going to use it when I get bad.' Instead of using it preventatively. But then I think people will say, "She hikes, she does some exercise, why is she using this disability permit?" I don't feel like going into a whole explanation.

I mean, even in the grocery store, I was almost stumbling, and my muscles were cramping stiff, and I probably could have used one of those wheelchair carts they have, but I didn't use it. I just looked at it ... (I thought to myself) 'Oh, I don't need

that. Nobody's going to believe that I need that. I can still walk. I might be stumbling but I can still walk.' Instead of thinking, 'this will help me to not expend any more energy and help me recover faster.'

30 Persons with a hidden disability may feel under constant surveillance when utilizing necessary accommodations (Samuels). An individual may feel self-consciously 'on' at all times (Goffman). Victoria describes this experience:

My handicap (placard) hangs. And when people see my car, I'm always thinking, "Oh my gosh, what are they thinking right now?" And I'm always thinking, "They probably don't think it's me." Someone will come up and say, "Why do you guys have a handicap (placard)? What's that about?" It's hard because people will look at me and not think that something's wrong. I think that's the hardest part ... having people looking at me and not thinking that there's anything wrong.

Gendered Disability 'Performance'

31 Each bodily and social performance is shaped by, and even confined to, the cultural values, norms and expectations of the particular situation. Such gender expectations have significant consequences for the bodily performance of persons with a hidden disability. Women with disabilities are expected to maintain a dramaturgical performance that embodies vulnerability, inferiority, and dependence (Asch and Fine). While these societal notions stand in stark contrast to ideals of masculinity, they epitomize femininity (Garland-Thomson). Women are supposed to be submissive, sensitive, romantically appealing, and dependent, while appearing healthy, due to the social value placed on their bodily appearance and nurturing role (Abrams; Asch and Fine; Johnston and Sinclair; Vickers). Understanding the pervading emphasis on exterior appearance and beauty and on the importance of the ability to disguise bodily limitations will allow insight into why women may be likely to conceal a hidden disability (Stone).

32 The long-standing feminist movement against a patriarchal society rages against women being taught that their individual worth is based on how closely and how favorably their bodily appearance comes to desirable objects (Mairs; Stone). While standards for appearance significantly affect women, ironically it is the stereotype of femininity that allows for certain coping mechanisms for women with a hidden disability. There is more societal acceptance for them to access the resources necessary to adapt to their conditions. Therefore, they show greater resiliency (Charmaz). Angela describes how being female and knowing that society accepts her dependence upon others allows her to request the help she needs:

I would prefer not to have seizures by myself, and (with epilepsy) you have to depend on someone. Someone has to help me. It's scary to have a seizure by myself. Because usually when I have a seizure they have to turn me on my side. So if I had it by myself, who's going to turn me on my side? I'm going to choke on my throw up or my

blood and I might suffocate. It bothers me that I have to be dependent, but it doesn't bother me asking for help when I need it. I could see a guy being more embarrassed to ask for help and to be like, "I'm epileptic."

33 Women are socialized into developing a high level of understanding of the intricacies of human relationships (Abrams; Greenhalgh). They tend to place more importance on social interaction with others, and they seek out the opportunity to lean on and learn from others when coping with life's hardships (Abrams; Petronio, Martin, and Littlefield). Rosalina believes this is the cause for the gender discrepancy in her support group:

It seems to me the guys have a lot more trouble staying on (the diet) than girls. Even our support groups are maybe seventy-five percent women. I think it's because it's a lot easier for women to bond and talk about ways they've found to make a bread that comes out lighter and exchange recipes. It becomes a therapeutical woman's world type of thing, of how to make gluten-free things or order online products and making those and baking those. Men don't really go out of their way to learn how to make special recipes or share recipes with anyone. That's been a huge thing of the diet; finding the foods and finding gluten-free things. Men are more, "Leave me my steak and my potatoes and hold the bread." Also, I think the men consider the women weaker than them, like, about stomach pains or anything that's wrong. With them, they'll get sick, but they're not going to be telling anyone else about it—they're just going to try to keep it to themselves. Men don't want to be admitting weakness. The women are a lot more open with how sick they were and how it affects them.

34 Women's self-esteem is gained through their connection to others (Abrams). Thus, accessing peer-support contributes to both positive identity development and resilient coping skills. A woman's success, however, still hinges on her ability to conform to the societal standards of appearance. In today's society, the dominant ideal for a women's appearance is to have a body that is as thin as possible. Victoria describes that it was this very preference in the female body that allowed her to escape the social ridicule a male with the same condition faced:

Being thin and being little, because of the arthritis—being skinny isn't a factor when you're female, but it's probably definitely a factor when you're male ... I know a kid that gets beat up because he is so small because arthritis stunts your growth. They see him, and they put him in the lockers. They beat him up and he has to deal with a whole other set of challenges that I would never have thought of. So he left school early and got his GED because he couldn't deal with all the ridicule.

35 Women with unapparent conditions may find themselves suspended between their day-to-day experiences and the ideals of feminism (Sherr Klein). Some aspects of patriarchy benefit their daily coping; other aspects remain oppressive. Displaying less than perfect elegance, poise, and bodily integrity, women with disabilities are frequently rejected by both mainstream patriarchy and the feminist movement (Asch and Fine). Feminism is preoccupied

with projecting an image of autonomy, strength, and competence; an image that women with disabilities do not embody. Meanwhile, other 'feminine' roles, like motherhood, are called into question for women with disabilities (Sheldon). Powerful economic, social, and cultural forces reduce the autonomy of women with visible and hidden disabilities of all forms to become mothers and for women to give birth to a baby with a disability (Sherry). Victoria describes such a confrontation:

I told one guy (about my condition), and he told me I shouldn't reproduce. I was in high school. "You shouldn't reproduce," he said. He was a friend. And I was just like, "Really?" Now it bothers me. I feel like calling him and telling him what I think. But then I was just like, "Hmm."

36 Women with disabilities are counseled away from motherhood, routinely persuaded that their own health will be jeopardized, or that the baby might inherit the 'problem,' or that their own impairments will keep them from being a good mother (Edwards and Imrie; Sheldon). I can relate to many females with disabilities who are confronted at a very young age about how to prevent the birth of a child like ourselves. I was still a child, only twelve years old, when I heard the first of many warnings, "When it is time to think about starting a family, I strongly suggest..." Procreation was the furthest thing from my mind, but the medical model was becoming etched in my psyche: prevention of more disability at all costs.

Conclusion

37 Ultimately, women with unapparent disabilities are juxtaposed between influential societal ideals of what it means to be a woman and the feminist call to resent and resist such oppressive standards. Some standards are entirely out of reach, while others assist and abate their daily struggle, presenting these women with a complex paradox.

38 When I 'discovered' feminism, I remember feeling enlightened, empowered, liberated. The more feminist literature I became immersed in, the more it became engrained in me that anything but complete independence and autonomy goes against the tenets of feminism: "I can do it myself. I am a woman, hear me roar!" This idea made me hate the ways that I am not independent; it made me feel guilty for the ways I have used my femininity to my advantage in soliciting help. When I became involved in disability studies, I learned that I am not alone in the observation that feminism neglects women with disabilities, as we are perceived to embody stereotypically feminine qualities (Sherr Klein; Sheldon; Fine and Asch). Prolific in the literature are accusations against the feminist movement for undermining the struggle of women with disabilities in pursuit of advancing power and potency (Fine and Asch; Morris; Garland-Thomson). My definition of independence changed

when I read George Bernard Shaw's quote (1916) posted on a Society for Disability Studies listserv email: "Independence? That's middle class blasphemy. We are all dependent on one another, every soul of us on Earth." It was an epiphany for me. I *can* ask someone to lift my carry-on into the storage compartment in an airplane, or to unscrew the cap off my water bottle, or to open a heavy door, without batting my eyes and raising the pitch of my voice. I can be an *interdependent* woman, a feminist, *and* I have physical limitations. I can be weak in body without being weak in spirit. I, like many women with a hidden disability, am learning how to live in paradox.

39 Women with hidden disabilities learn to transform their identity and needs depending on the situational context. With a foot in both the nondisabled and the disability worlds, they both belong to both and fit completely into neither. The hidden disability is framed differently minute to minute as it is integrated into the individual identity as a "flexible continuum of responses that folds back on itself in various directions in response to myriad of internal and external factors" (Olney and Kim 4). By better understanding the commonalities and differences present in the individual experience of hidden disability, women with hidden disabilities and their support system may benefit from hearing a story they can relate to, become empowered for healthy preservation of self, and they might receive the message that, although it may feel like it, they are not alone in this limbo between the nondisabled and disabled worlds.

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“What the Books Told”: Illness, Witnessing, and Patient-Doctor Encounters in Martha Hall’s Artists’ Books

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Abstract:

The essay explores the specific insights artists’ books offer to contemporary feminist understandings of breast cancer, questions of representation and embodiment, discourses of ‘witnessing,’ and to doctor-patient relationships, using the work of American book artist Martha A. Hall as a case study. Hall’s artists’ books, created in response to her initial diagnosis of breast cancer in 1989 and the effects of later recurrences until her death in 2004, consist of poems, prose passages, ironic quotations by health practitioners, and images such as x-rays, bone scans, and pictures of prescription bottles. Artists’ books create a different kind of ‘reading experience’ compared to most ordinary books. While this is often described in terms of a powerful ‘aesthetic’ experience, in the essay I am more concerned with illustrating how artists’ books engage and complicate discourses of witnessing, which have recently become foregrounded in the fields of trauma, disability, and illness studies. I also discuss the potential the artist’s book holds as a medium for sharing experiences of critical illness and for effecting change in the ways medical professionals interact with their patients, thus commenting on both its personal and political value. The essay concludes with a series of reflections triggered by my own particular encounter with Hall’s work.

Through certain books, a truth unfolds. Anatomy and physiology, The tiny sensing organs of the tongue— Each nameless cell contributing its needs. It was fabulous, what the body told. (Rafael Campo)

1 Martha A. Hall created around a hundred artists’ books in response to her initial diagnosis of breast cancer in 1989 and the effects of later recurrences until her death in 2004. Leaving a new career in New York City as a business executive after being diagnosed with a recurrence of breast cancer in 1993, and returning to art, which she had studied as an undergraduate in Smith College in 1971, Hall took a series of art courses and workshops in book making, and familiarised herself with several printing and binding techniques. Her books vary in size, are made of diverse materials, and are either hand-bound or of folded or accordion construction. Most of them are in limited editions while a few exist only in the original. The books do not only combine words and images, including stamped designs, ink drawings, and acrylic paintings, thus embodying a new form of “visual literature” (Rice 59); they also contain medical artifacts such as X-rays, pill containers, prescribed medications in original envelopes and appointment cards, as well as black and white photographic prints,

hairs, and other memorabilia. Some of the books are housed within handmade boxes of different shapes and sizes.¹

2 Artists' books, as most art historians agree, "mark a genuine historical moment of dissatisfaction with art's outreach, a declaration of independence by artists who speak, publish, and at least try to distribute themselves, bypassing the system" (Lippard 50). These developments are more typical of the second half of the twentieth century. Hall does not specifically allude to such literary/political origins of the artist's book as independent publishing or activist art. However, in her artist's statement included in *Holding In, Holding On* (2003), a catalogue accompanying a travelling exhibition of her books in several US colleges and libraries, Hall writes that besides offering her a way "to have a voice in the world," her books are "a means to effect change in the way medical professionals interact with their patients" (15).² A series of artists' books have been used for the benefit of public causes,³ and in "The Artist's Book as Idea and Form," book artist Johanna Drucker writes that the question as to "whether such work can result in a change of political structure and policy opens the door to another set of debates about the role and function of art in the 20th century."

3 Two critics who have contributed to this discussion specifically addressing the theme of illness, as well as Hall's work from a sociological perspective, are Alan Radley and Susan Bell. In a recent article, which examines Hall's work together with that of British photographer Jo Spence, they convincingly argue that visual images are important for "their anchoring potential in social practices surrounding breast cancer" while they also function as survival strategies and a source of social support for individual women who cope with life-threatening illness (369). While Spence's work has been the object of much critical discussion, to my knowledge there is hardly any work focusing on Hall's artists' books other than the article mentioned and an earlier one by Bell, which equally revolves around the "benefits of a *visual sociological* imagination" (37, emphasis added). At the same time, while there are many studies on the personal, cultural, and political work illness narratives do and, more specifically, on the interventions of various genres of breast cancer literature,⁴ there has not been an explicit focus on the kind of insights artists' books, in particular, can offer to

¹ Images of Hall's books can be seen at <http://www.smith.edu/news/2004-05/MarthaHall.html>.

² All pages of quoted excerpts from Hall's books, Hall's artist's statement, and Letha E. Mills' foreword refer to the exhibition catalogue *Holding In, Holding On* (2003).

³ See Hubert and Hubert for examples of artists' books that have been used in this way, particularly pages 123-47.

⁴ A recent book on five genres of cancer literature by women is Deshazer's *Fractured Borders*.

contemporary feminist understandings of breast cancer, questions of representation and embodiment, or to discourses of “witnessing” and to doctor-patient relationships.

4 Certainly, there are a number of better-known artists’ books which deal with experiences of illness, but they are often discussed in a different context or with different aims in mind. This results in marginalising the topic of illness, even though the technical excellence of the books is directly relevant to the demands posed by precisely such a topic. To mention a few examples, Scott L. McCarney’s *Memory Loss* is about his brother who had an automobile accident in 1985 that left him with traumatic brain injury. The book, which uses an accordion binding, is, in the artist’s words, “meant to be experiential, putting the viewer in the space of having only sporadic access to a lifetime of memories.” Similarly, Susan King uses the maze at Chartres Cathedral in France as the structure of *Treading the Maze: An Artist’s Journey through Breast Cancer* (1993). The book places the reader/viewer in the role of a pilgrim, walking into the maze of illness and back out again. In a chapter on artists’ books as “visual literature,” Shelley Rice briefly mentions three books which are of interest: Matthew Geller’s *Difficulty Swallowing*, which provides a medical case history of the artist’s partner who eventually dies of leukemia; *Thirty Five Years/One Week*, which is Linn Underhill’s memorial to her sister’s illness—there is a clear division of labour as the photographs included in the book document the sister’s normal life while the excerpts from the diary deal with her illness; and, finally, Nancy Holt’s *Ransacked*, which also consists of photographs and text, and which tells the simultaneous story of the gradual decline of Holt’s dying aunt and the falling apart of her house as it becomes invaded by a manipulative nurse (62-64).

5 It becomes obvious from this short overview of artists’ books with illness as their theme that, like other illness narratives, the authors/artists need to make certain choices when it comes to their narrative strategies, such as, for instance, create a balance between the clinical and the metaphorical, adopt a personal or distanced tone, or use a structuring motif to provide coherence and draw in readers. However, the specific characteristics of the artist’s book medium, such as its “complexity, density, and intimacy” (Drucker, “Cultural Status” 41), means that artists’ books create a different kind of “reading experience” compared to most ordinary books. While this is often described in terms of a powerful “aesthetic” experience, I am interested in exploring how artists’ books engage and complicate discourses of witnessing, which have become foregrounded in the fields of trauma, disability, and illness studies. In the epigraph that opens this essay, poet and physician Rafael Campo writes that “through certain books a truth unfolds” (*What the Body Told* 122). Another topic I address in

the essay is what kind of truths artists' books can communicate to medical practitioners, and what kind of changes they can initiate or facilitate in perspectives and attitudes towards illness and patients. Hall served for years on the Board of Cancer Community Centre, in South Portland, Maine, and received invitations to speak to medical professionals in hospitals and colleges. She decided she would like her work to be in public, rather than private, collections, particularly college libraries. Her books are currently used in Medical Humanities units, and the Maine Women Writers Collection, which owns twelve of her books, regularly receives requests to have the books used in medical schools across the United States.⁵ If the book as a cheap, portable, and accessible object has the capacity (at least in theory) to enter numerous locales, and to transform the viewers' expectations, what impact could artists' books have on future physicians and the medical community in general if they were to be used in this way?

I

In the old art the writer writes texts. In the new art the writer makes books. (Ulises Carrión)

6 Artists' books challenge reading conventions associated with ordinary books. Breon Mitchell characterises the reading of an artist's book as "a performance"; the "ideal" reader is someone who "plays" the book, "actualising" the various elements the artist has built into it, such as its shape, size, format, colour, texture, typography, and, possibly, sound (162). While Mitchell emphasises the unique aesthetic experience artists' books offer, and argues that very few people have *really* "read" artists' books, in turning to Hall's books I wish in this section to consider how the central question of how one reads artists' books becomes modulated when the topic is life-threatening illness.

7 There are many ways in which the formal means of realisation and production are integrated with the thematic or aesthetic issues in Hall's books. Breast cancer writing has focused on embodied imagery such as the surgical scar, but, through the process of making books, Hall seems to perform her own version of surgery in ways that are not merely symbolic or metaphorical. The binding of a book is similar to the scar as it is the site where the pages of the book stitch together and come apart. Campo suggests that "writing good iambic pentameter feels like putting stitches into the anonymous, eternally gaping wound of being human, and [that] rhymes can be intertwined like surgical knots" (*Desire to Heal* 116); Hall's stitches are clearly more tangible. In 1999, Eve Kosofsky Sedgwick, who had become

⁵ Information on the "Martha A. Hall Collection, 1998-2003" at the University of New England can be found at <http://www.une.edu/mwwc/research/hallm.asp>. I am grateful to Cully Gurley, curator of Maine Women Writers Collection, for her help and for giving me permission to use the film *I Make Books* in my research.

more and more interested in art and weaving after her cancer diagnosis, exhibited a series of cloth figures she had made—“stuffed forms dressed in blue leggings and tunics, draped with woven cloth”—and hung from the ceiling as part of an installation that temporarily filled the lounge of the City University of New York Graduate Center (Miller 221). As Sedgwick explains, “[t]he figures’ strongest representation ties were to the disorienting and radically denuding bodily sense generated by medical imaging and illness itself on the one hand; and on the other, to material urges to dress, ornament, to mend, to recover, and heal” (qtd. in Miller 221-22). While most of Hall’s books are the result of an urge to mend or ornament (Hall was a former professional weaver), in other cases the process of creation is driven by a desire to destroy. A good example is the book *What You Don’t Want to Know* which functions like a palimpsest. Hall created this sculptured book by pulling apart and reassembling a publication of the National Cancer Institute entitled *What You Need to Know about Breast Cancer*. In her artist’s statement, she writes that “the process of stitching, crumpling, tearing, cutting, and stapling the pages helped [her] express and release anger” (13). But this book does not only have therapeutic value. Erasing parts of the original text, altering the title and substituting new words and images, Hall “writes back” to the official medical narrative and reclaims part of her agency. Given that the new book is composite as it is held together by different voices, it becomes a site of struggle over the meanings ascribed to breast cancer.

8 The binding of a book is not only the site of trauma and healing. Canadian book artist Lucie Lambert suggests that the binding “is a container, a wrapping, a *skin*, a meeting point *between the content and the potential reader*” (qtd. in Plesch 221, emphasis added). Artists’ books, like other physical objects, do not exist primarily as vehicles through which ideas are accessed “but as objects that mark and incite bodily contact, exerting the force of the tangible upon the touching body” (Tanner 202). Hall’s books also bear the body’s marks and hold its traces through the inclusion of hairs as well as autobiographical objects, such as used medical appointment cards and original prescription bottles.⁶ Writing about objects of grief, such as the AIDS memorial quilt, Laura Tanner argues that “thinking about the way we know objects [...] in and through the body allows us to resist the pressure of immaterialization that would exclude palpable, multisensory experience not only from the realm of knowledge in general but from our understanding of grief in particular” (209). Still, Hall seems to perceive the threat posed by the viewer’s literal contact with her books: “People may not want to

⁶ Other artists’ books by women explore bodily emissions and traces left by the body. The most well known, perhaps, is *Emissions* (1992), a collaboration between Susan Johanknecht and Katharine Meynell.

‘touch’ the topics I explore in my books; yet the books invite handling, touching, interaction” (14).

9 Touch constitutes a central element in the reading process of artists’ books. The choice of paper conditions and enhances the viewer’s tactile experience of a book and of its contents. In the book *Shell Bones*, for instance, thick and strong heavyweight wrapper is used. This conveys through touch what the story of the book is about: finding thick and strong shells on the beach, which remind Hall of bones, and taking them home. In the case of other books, their construction requires a specific way of interacting with them. A good example is *Jane, with Wings*, which uses a multi-layered folding structure. A polished stone serves as a knob for lifting the red cover of the black box that houses this book; it is an invitation as much as it attests to the need of secrecy. Radley and Bell are right to note that “to read this book is perhaps above all to learn to handle it”:

To read the words one has to handle the book very carefully, going deeper into the ‘origami’ folds so as not to tear the paper; unwrapping (not turning) the pages so as to read the words. [...] The power of the book is in the physical unfolding, in the contiguous relation of revealed pages of text that speak of closing, hiding, and ultimately of difference. (381-82)

While the construction of *Jane, with Wings* invites opening, the text advises the reader to “close it away,” creating, I would argue, a productive tension:

Close it away.
The fear ...
Close this page.
You are not
The one
Who is dying.
You do not
Need to see
Beneath the surface
The skin,
The scars. (56)

10 The delicate boundary between concealing and revealing that this book negotiates seems apt when it comes to thinking about narratives that explore illness as well as other traumatic experiences. An appeal for recognition and empathy is made more difficult when the narrative addresses people who do not suffer from the same condition as in the case of *Jane, with Wings*; through the pronoun *you*, this book does not only relate the reader to the author but also the healthy to the sick. Shlomith Rimmon-Kenan examines the narrative strategy employed in Gillian Rose’s memoir *Love’s Work*, whose first part does not read as an illness narrative at all. Rose, who recounts her experience with ovarian cancer, confronts the

anxiety of losing the (presumably disease-free) reader in a self-reflexive moment in the middle of the narrative, but through her deferred account effectively “manipulates the reader into continuing to read in spite of the emotional difficulty” (Rimmon-Kenan 248). Hall’s books present a similar challenge to both “our conventions of reading as well as to our attitude toward illness” (Rimmon-Kenan 248), but utilise strategies specific to the genre of the artist’s book: At first glance, the reader/viewer is faced with the creativity and uniqueness of the books as works of art, as well as with their inaccessibility, and is therefore lured into opening them (or the boxes in which they are housed) without, in most cases, knowing what to expect. Given that the books are handmade, and, in many cases, handwritten, there is a much more immediate sense of exploring privacy; the reader, inevitably, takes the role of *voyeur* but soon realises that the book makes different demands on him or her. By that time, however, it is difficult to withdraw, not only because this goes against reading conventions (namely, against the desire to reach the end), but also, because, not unlike Rose’s memoir, it is as if the text says: “You can’t leave me now that you know my condition” (Rimmon-Kenan 248).

1 It is clear then that reading *Jane, with Wings* does not only entail handling it with care so as not to tear the pages. It also demands taking up the interactive/ethical challenges the book presents. Radley and Bell, drawing on Bruno Latour, write that the work of representation in artworks is “aimed at engaging the viewer in order to bring before her the ideas and values that are mediated by the signs” (385). As they are right to point out, “[t]heir message is about *the viewers/readers currently engaging the work*, and what these individual might do *now*. It is not just about the disease in general, or the fate of individuals who once shared their diagnosis” (Radley and Bell 385, emphasis in the original). Coming back to Mitchell’s idea of performance, *Jane, with Wings* can be thought of as a kind of *interactive* art which constructs the reader as responsible, in Kelly Oliver’s sense of “response-able” (7), and therefore engages him or her as witness: Whether one chooses to advance in the reading of the book or not, there is no way not to interact; the piece already through its form and text establishes a relation between writer and reader/viewer.

12 While *Jane, with Wings* seems to compel a specifically ethical form of engagement, the reader (even the “ideal” one who reaches the book’s centre) is paradoxically told that he or she is to close the book without knowing, without seeing. The book demands *and* exceeds a response at the same time. However, what may initially seem like a performance of failed interaction can in fact transform us as readers in that it compels us to bear witness to what is, in Oliver’s phrase, “beyond recognition”, namely the process of witnessing itself. Oliver

writes that “we must be vigilant in our attempts to continually open and reopen the possibility of response” (19), and *Jane, with Wings* does precisely that by drawing attention to both the necessity and the impossibility of fully witnessing another’s experience. In my conclusion I return to this idea and consider the significance of my own particular mode of encountering Hall’s work “in the here and how”, which, through its mediated proximity to the other, keeps open the possibility of future witnessing.

II

I would like a doctor who *enjoyed* me. I want to be a good story for him, to give some of my art in exchange for his. [...] Just as he orders blood tests and bone scans of my body, I’d like my doctor to scan *me*, to grope for my spirit. [...] Without some such recognition, I am nothing but my illness. [...] [The doctor] has to dissect the cadaver of his professional persona; he must see that his silence and neutrality are unnatural. It may be necessary to give up some of his authority in exchange for his humanity. [...] He has little to lose and everything to gain by letting the sick man into his heart. (Anatole Broyard)

13 Hall’s books critique medicalisation and objectification, namely how bodies of cancer patients are handled during surgery, radiation, and chemotherapy, in various ways. Several of Hall’s books were inspired by specific interactions with her physicians and nurses. As in Anatole Broyard’s essay “The Patient Examines the Doctor,” from which the epigraph of this section is taken, through her books Hall shows what kind of qualities she would like her doctors to have. In her book *Just to Know*, she literally examines the female technician who administers radiation therapy:

“Take in a deep breath. Hold it.” The test. The technician’s voice sounds eerie, comes from a speaker in the machine. She is in the other room, eyes on the computer, not me. The machine whirls softly as if something is spinning around and around at high speed inside. “Breathe.” The machine moves forward a fraction of an inch. “Take in a deep breath. Hold it.” Then the muted whirling sound. “Breathe.” Again and again. Perhaps a hundred times. She must be tired of repeating the same phrase. (20)

In his memoir *The Desire to Heal*, Campo draws a compelling comparison between “withholding words” through the conscious process of “forbidding [him]self the application of heartfelt, meaningful language” and that of commanding his patients “to hold their breath” (114). Hall seems to suggest something similar about the technician in the above excerpt. In *Test Day*, like Broyard, Hall distinguishes between scanning the body and scanning the self, expressing her anger at her doctors’ unwillingness to see her as anything more than her illness:

I will light up their screens,
My insides black and white.

Circles, shadows, lines.
But the watchers will not see me;
Will not see my self, my soul; (38)

14 Broyard writes: “To the typical physician, my illness is a routine incident in his rounds, while for me it’s the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity” (43). *Small Rooms*, a book which is made to look as a series of examination rooms, dramatises this incongruity: “The nurse asks [Hall], ‘And how are you today?’ I answer, ‘I’m in terrible pain.’ And she responds, ‘Oh. I like the color of your sweater.’ She doesn’t look at me” (70). The text evokes a never-ending cycle of superficial interaction rather than meaningful communication between patients and doctors: “I leave the long corridors, the waiting women, the nurses and doctors asking someone else, ‘And how are you today?’” (72). Another book in which repetition is central is *Prescriptions*. Hall expresses her agony with the number of pills she needs to take and with her doctors who are quick to prescribe them. The pages of this book, which consist of transparent leaves with photocopies of prescriptions and pill containers, and the refrain in the text “I have too many prescriptions” foreground her feelings of frustration.

15 In his study *The Renewal of Generosity*, Arthur Frank argues that “the physician dreams the monological authority of being the single unquestioned voice. The patient dreams the monological passivity of having this other pronounce their truth” (103). Letha E. Mills, one of Hall’s physicians, who opens *Holding In, Holding On* with a statement on Hall’s books, notes that because “medical evaluation of disease has become highly technical” there is so much waiting that a patient’s “future hangs in the balance, determined by ‘how well they did’ on the test” (8-9). In the book *Test Day*, already mentioned, the condition of passive waiting is communicated by bringing together the idea of women’s infantilisation with the kind of infantilisation inflicted upon patients by the medical community, which has been heavily criticised in illness narratives of the eighties and early nineties. The silent patient is also compared to an obedient pupil who needs to do as told in order to earn a passing mark:

I will be obedient,
As if my desire to please
Will earn me good grades,
A passing mark.
Small child thoughts
In my woman head.
[...]
I will do as I am told. (38)

In her book *Anxiety (to Martin Antonetti)*, Hall emphasises waiting by alluding to her double identity as artist and cancer patient. The book starts with Hall waiting for Martin (curator of

rare books in Smith's Mortimer Rare Book Room) to call in order to let her know whether he will buy her book entitled "The Rest of My Life," but her anxiety quickly shifts; the book closes with Hall waiting for her doctor, this time, who will call her "about *The Rest of My Life*" (59, emphasis in the original), not a book with this title, but literally the rest of her life. *Anxiety* emphasises feelings of dependence by evoking Hall's insecurity about the future of her art *and* of her life, which remain inextricably connected. The book is an atlas foldout, and symmetry is created as the top part concerns the curator and the bottom the doctor. Since its form does not dictate a single way of reading it—as it does not involve turning pages, the book can be read either horizontally or vertically—the conflation of identities and positions intended by Hall is foregrounded.

16 *Voices: Five Doctors Speak*, which was made into an edition of twelve, emphasises the interpersonal dimension of medicine in an intriguing way. The book reads like a theatrical play or script—if one is accessing this book through the exhibition catalogue *Holding In, Holding On*, there is a section at the end which provides information on the "cast" by giving the full names corresponding to the five voices, distinguished in the text through the use of their surname initials. However, this is not how the original book sorts out the various voices. There, a different font and paper are used by Hall to differentiate each doctor. *Voices* also consists of skull, eye, and skeleton stamped images and of a miniature book entitled *Legacy* attached to one page inside an envelope. This idiosyncratic script can be better described as a series of monologues since the voice of the patient is not audible. The choice not to turn the sections of which this "performance" consists into dialogues is perhaps a statement in itself: Medicine takes away the voice of the patient, which returns us to Frank's idea of the doctor's "monological authority."

17 *Voices* documents what five doctors each said to Hall when telling her about her second recurrence of breast cancer over a six-day period (July 7-16, 1998), and they can be read comparatively to emphasise different approaches and patterns of interaction between doctors and patients. Some of the voices are more generous, and though they communicate the same bad news, do so with more empathy and caring, while others consist of thoughtless comments ("Four and a half-years is not bad"; "We are buying time") or superficial interactions and uncaring comments ("Do you want to speak to me on the phone or in person?"). A few of the voices contain condescending or patronising comments ("You are my poster child. You've done so well") or, on the contrary, blame the patient for failing to do well ("You've failed"), sustaining the ideals of female infantilisation and dutiful compliance already mentioned. In *I Make Books*, a documentary created by the University of New

England Media Services Department in 2003, Hall explains that the doctor who said that she had “failed” used the term merely “in a medical-terminology sense,” but it was only after she confronted that doctor that the burden she had to carry for a long time softened. In the same film, Hall explains how she uses the books to communicate with her physicians, doctors, and the medical community in general. She did show *Voices* to all of her physicians, including the one she was most angry at, who delayed seeing it providing various excuses. As she writes in her artist’s statement, the book “elicited various responses including denial, disbelief, and discomfort, but overall using the book to communicate with physicians and nurses has a positive impact on her interactions with the medical community” (13).

18 In his chapter “Physicians’ Generosity,” which draws on Bakhtin’s work, Frank argues that identification with others requires giving up the monologue; dialogue is achieved when a “physician reconstitutes him- or herself *in the voices of his or her patients*” (101, emphasis in the original). In Hall’s case, we also notice a reverse process taking place, which confirms the mutual positive impact meaningful communication between doctors and patients can have. One of the voices, belonging to her female doctor Mills, already mentioned, tells Hall the following: “In order to live you must live with the fear of dying. Your books will be your legacy, for family and for friends. And if you live to be an old lady you’ll reminisce” (26). As Broyard writes, “Whether he wants to be or not, the doctor is a storyteller, and he can turn our lives into good or bad stories, regardless of the diagnosis” (53). Mills’ statement encouraged Hall to continue to make books, and inspired the miniature book *Legacy*, made in March 2001, which she decided to include in *Voices* as a separate book, using the image of a dancing skeleton to dramatise her doctor’s story. It serves as an example of the patient, this time, reconstituting herself in the voice of her practitioner. Hall of course shows the finished book to all her physicians, which means that now that Mills’ words have been transmuted into her patient’s book, the doctor can also reconstitute herself in the voice of her patient in future—the circle is complete but can open again. In her foreword to the catalogue, this becomes evident as Mills constantly returns to Hall’s work, speaking in her voice, in order to show the impact Hall’s art has had on her own practice and life: “Martha’s stories will speak to each of us differently and their meaning will change as we change and grow” (7).

19 The last page of *Voices* is a haunting page which is filled with a single phrase repeated on every line in all the different fonts of the doctors: “I am sorry.” The use of different fonts suggests that all of the five doctors have said that to Hall at some point. The litany of “I’m sorry” leaves barely any white space on the page creating the effect of concrete poetry or of a painting made of words rather than images. Besides causing a visceral response, it raises

questions concerning the frequency with which “I’m sorry” is being uttered by physicians and its implications: Is “I’m sorry” meaningful in any way or simply a distancing technique from an emotionally difficult situation as in the example of the voice by a doctor already discussed—“Let’s take this one step at a time. *I am sorry*. Do you want to speak to me on the phone or in person?” (25, emphasis added)? Does it evoke, instead, the difficult issue of failure (for either the patient or the doctor) to which I have already alluded? Medicine and science are resistant to the idea of failure: The modern medical narrative can only be sustained if progress and efficacy are confirmed through good survival rates for patients and expensive treatments that work rather than through the acknowledgement of victims, which belie the triumphant discourse of science. If through “I am sorry” a doctor relinquishes his or her authority, does this signal a shift from an emphasis on cure to care, which has been foregrounded in recent memoirs by doctors? Lisa Diedrich concludes her study *Treatments* with a chapter entitled “Towards an Ethics of Failure.” In it, drawing on Lyotard’s idea of the “*différend*,” which he defines as “an unstable state and instant of language wherein something which must be able to be put into phrases cannot yet be” (qtd. in Diedrich 149), Diedrich asks whether the process of truly addressing uncertainty, errors, failure, and suffering by the medical community, might be the beginning for a search to find “new rules for forming and linking phrases” between the subject positions of doctor and patient (150). For Diedrich, an ethics of failure “takes failure not as an ending” (as, for instance, in Hall’s doctor’s statement “We failed. You failed” in *Voices*) but “as a beginning” (166), and I suggest that illness narratives, like Hall’s books, which explore despair, frustration, and pain, can help the medical community take the risk of opening up to failure.

20 This possibility is not explored in the book *It’s Nothing*, an ironic title for a story of misdiagnosis. Hall insists that she is in pain, but since the tests do not show anything her judgement is disregarded. The new tests, however, reveal multiple lesions “there where I had shown you [to the doctor] I had pain. There where I had told you” (45). The medical notes mute this incident and present “aches which [the patient] has minimized and really brought out fully today” while they describe Hall as “slightly more depressed than she has been in the past” (45). Hall’s determination to “keep listening—to hear what her bones are saying” (45), at the end of the book, challenges the knowledge monopoly of doctors as well as the patients’ supposed ignorance. This book is interesting, in that like others in which Hall shifts between the positions of breast cancer patient and artist, it compares and contrasts the consulting room and the art classroom as spaces of body examination. The suggestion is that the latter can become a model for a more holistic approach to health and healing. The book starts with Hall

drawing the skull in art class while holding it cupped in her hands and proceeds to trace the rest of the body: “We gently moved our fingers down our vertebrae, felt for our first rib. [...] The next week we traced our sternum, pushed on our ribs” (44). While this exercise is painful (Hall hates “knowing where the jabs of pain would be—long ago memorized”), it is also a healing experience. The book concludes with Hall asserting the need to draw her body and pain: “So in art class I draw my ribs, my vertebrae, my skull. I draw my pain. I draw delicacy that hides anger, fragility that holds strength. These are my bones. I need to draw them to heal” (45). The lines she draws are not the same as the lines revealed by the bone scan. The emphasis on touching the body (feeling the different parts), which takes place in art class, complements the medical gaze, or “the machine vision” of “the watchers,” as Hall calls it, in *Test Day*. In turn, listening to hear what the bones are saying is a corrective to the doctors’ only and distant words: “‘Take a deep breath.’ ‘Hold it.’ ‘You can breathe’” (38).

21 In “Welcome to Cancerland,” Barbara Ehrenreich writes that “in the overwhelmingly Darwinian culture that has grown up around breast cancer, martyrs count for little; it is the ‘survivors’ who merit constant honor and acclaim” (48). The “mindless triumphalism of ‘survivohood,’” in Ehrenreich’s phrase, is perpetuated not only by science but also by the mainstream breast cancer culture, which “denigrates the dead and the dying” (53). Hall’s *Ghost Friends*, the last book I would like to mention in this section, is a moving card catalogue compilation of remembrances of similarly afflicted acquaintances, most of whom do not survive. It consists of sixteen books, each one of them sitting in an expendable file format. The bookcloth covered clamshell box in which they are housed creates a realistic filing cabinet expected to be found in a hospital or clinic. Hall supplements impersonal biomedical patient files, which document symptoms and treatment, and have statistical value through the particular stories of people she narrates. These stories fight facelessness, in that the individuals involved are named, and document both haunting and more optimistic moments by providing snapshots of encounters without passing judgement. For instance, one of them tells the story of Joyce who “walked into the treatment room and told us, the regulars, she had decided not to have chemo, not to fight anymore. She would not be coming back.” The story concludes with the comment “Her husband was crying” (66). *Ghost Friends* consists of lyrical elegies but also functions as a form of public memorialising that recalls the AIDS Memorial Quilt Project and other remembrance rituals. Several doctors, particularly those working with AIDS patients, have also attempted to do something similar. For example, in his poetry collection *What the Body Told* Campo includes a long sequence of deconstructed sonnets called “Ten Patients and Another,” through which he attempts to speak

for his patients in a literary rather than scientific language, thus humanising medicine. Likewise, Kate Scannell has a five-page list of names enumerating her dead patients in her memoir *Death of the Good Doctor*.

III

I make books.
I write what I cannot say.
I make marks with meaning only in
their making.
I paint in colors fearsome and strange.
I make books so I won't die.
The dialogue is something I am going to miss in letting my books go to an institution [University of New England] and I would hope that—I am carrying out half of the conversation—from time to time somebody would carry on another piece of the conversation. That would be a real gift. (Martha Hall)

22 If the artist's book as a medium can bring into being a different set of strategies for "doing illness," in Diedrich's term (25), how political are these strategies? In the "Martha Hall Collection" at the University of New England, together with twelve of Hall's books, there is a small amount of foldered material which belonged to the artist, including a copy of Ehrenreich's article "Welcome to Cancerland," to which I have briefly alluded. This article, which was published in *Harper's Magazine* in November 2001, diagnoses the circumstances behind the shift from the politicisation to the depoliticisation of patienthood, which occurred at the turn of the twenty-first century (Diedrich 48-49); its thesis is that there is "nothing very feminist—in an ideological or activist sense—about the mainstream of breast-cancer culture today" (Ehrenreich 47).

23 Hall's books do not establish links to radical activist agendas such as environmental or gay/lesbian movements and do not explicitly grapple with questions of difference, such as class and racial disparities, which often determine who is more likely to have access to health care and, possibly, better survival chances.⁷ However, as we have seen, they address discourses of victimhood/survival and infantilisation, which Ehrenreich takes issue with in her article, and express anger and frustration, thus questioning the "universally upbeat" stance that Ehrenreich finds disturbing in breast cancer patients (48). These are some of the threads of Ehrenreich's argument to which Hall seems to respond directly, but, by way of conclusion, I want to draw attention to a little detail in the article which I would like to imagine "spoke"

⁷ The fact that Hall does not deal with the invisibilities which, for instance, Audre Lorde, a black, lesbian woman with breast cancer addresses in *The Cancer Journals* (1980), is inevitable given the position from which she speaks: that of a middle-class white heterosexual woman, who has better access to health care and treatment than, for example, women from poor backgrounds.

to Hall in a certain way, though of course this is speculation. While commenting on the ultra feminine and infantilising theme in breast-cancer discourse, represented by the teddy bears and the prevailing “pinkness,” Ehrenreich specifically refers to the contents of a bag distributed to breast cancer patients, which, besides cosmetics, includes, to her amazement, “a small box of crayons” (46). The founder of the Foundation who distributes these bags, explains what the crayons are for—they go with a journal and sketch book also contained in the bag “for people to express different moods, different thoughts”—but admits to Ehrenreich that she has never tried to write with crayons herself (46). Now, thinking of Hall’s artists’ books discussed in the previous sections, I would like to suggest that, rather than negating writing, and its power, crayons can, in Drucker’s phrase, “extend its communicative potential” (*Figuring* 18). “Painting in fierce colors” and “making marks,” which is how Hall describes the process of making books in her book *I Make Books* from which the first epigraph of this concluding section is taken, is not a solipsistic or merely ornamental activity that promotes infantilisation. It is neither dictated by the parameters of American consumer culture, which is what Ehrenreich finds troubling about mainstream breast cancer culture. While surveying the pink-ribbon-themed breast cancer products, Ehrenreich notes that “I can’t help noticing that the existential space in which a friend has earnestly advised me to ‘confront my mortality’ bears a striking resemblance to the mall” (46). I am not suggesting, of course, that all women with breast cancer should become book artists so that the mall can give its place to what is often perceived as a more elitist space, namely the art gallery, even though, as already mentioned, artists’ books often operate outside the constraints of the art market and gallery system.⁸ Even so, creating a book and sending it out to the world is different from putting down thoughts in a diary that will not be read by others. As Drucker writes about printing, an important component of book making:

It provides a fundamental means of transforming personal expression into an authoritative form within the social order and the public sphere. The physicality of printing makes that transformation a somatic experience, an act of the body, which moves the interior voice, the personal word, into the cultural domain. (*Figuring* 4)

The implication is that not all women who write about their illness or create artifacts can reclaim discursive authority, but my point is that writing and drawing do not only serve to communicate personal experiences. Artists’ books are a means through which some women can have a voice; they are therapeutic, but also political insofar as the books are shareable, can provide insights to the process of witnessing and enlarge its circle, and, finally, as we

⁸ Stephen Bury suggests that one of the reasons why artists’ books are particularly attractive to women is because these systems are still male-dominated (22).

have seen in Hall's case, can be used to effect change in the ways medical professionals interact with their patients.

24 Artists' books together with ordinary books exploring illness can become part of a doctor's training in the context of the ongoing development of medical humanities curriculum units. Like a literary scholar, the doctor is faced with a text, a narrative voiced by the patient, which has to be interpreted. The advantage of artists' books over ordinary ones is that materiality is foregrounded so that, rather than merely having symbolic status, artists' books constantly return us to the body. Like patients, artists' books have to be examined, touched, unveiled, opened, but require physical intimacy and care. They also exemplify different ways of approaching the process of examination itself: Artists' books can be seen from either a clinical distance or close at hand where turning or unwrapping the pages uncovers more personal feelings and struggles, just as "reading" a patient involves more than anatomy and physiology or conducting a set of bodily scans.

25 Ultimately, the books can open up a new space of communication between patients and doctors that can renew intimacy and generosity, and even reclaim an alternative form of silence:

I am afraid
To speak my fears aloud,
[...]
to hear your answers,
to know what you know,
so do not tell me.
Just turn the page
And close the book.
Do not tell me
now. (86)

The above excerpt is taken from Hall's book *Tell Me*. The book stages a silent but meaningful interaction between herself and her doctor; involving a form of communication beyond words, mediated by the book that connects the doctor and the patient as if it were a skin. The doctor is asked to simply turn the pages of the book, as if partaking in a silent ritual, and delay telling the patient what she fears to hear. Considering the importance of "an ethics of touch," Sara Ahmed writes that "thinking of speaking and hearing in terms of touch might allow us to challenge the very assumption that communication is about expression, or about the transparency of meaning" (155). Transparency is what is aimed for in patient-doctor exchanges (in most contexts), even though the emotional difficulty entailed makes communication difficult. This is why neutrality and silence, in the form of withholding words that can touch another person's heart, are opted for by the doctor, and sometimes by the

patient too. However, as Ahmed adds, “[c]ommunication involves working with that which fails to get across or that which is necessarily secret” (155).

26 Turning to my own *particular* encounter with Hall’s books, I would like to finish with a few brief reflections on the responsibility that is opened by that which fails to get across or cannot be grasped in the present. “What am I experiencing when I turn these pages? This is what the critic of an artist’s book must ask,” and, as Dick Higgins adds, “for most critics it is an uncomfortable question” (12). As he clarifies: “The language of normative criticism is not geared towards the discussion of an experience, which is the main focus of most artists’ books” (12). I would like to further complicate this statement. If, as suggested, artists’ books invite touching and handling, that is, they compel not only involvement with the ideas expressed in the text and the images, but also *physical* engagement, how is it possible for me to respond to Hall’s books “in a way which is generous, in a way which gives” (Ahmed 149), when proximity is mediated and thus one cannot get close enough to the other?

27 In a chapter on ethical encounters, which draws on Levinas’ work and Derrida’s ethics of hospitality, Ahmed stresses the need for a more proper and rigorous thinking of what it means to encounter an other by shifting our attention to the question of particular *modes of encounter* through which others are faced. Reading Ahmed’s lyrical and moving description of her encounter with Indian writer Mahasweta Devi and her fictional character Douloti, I am tempted to draw parallels and comparisons. Although my encounter with Hall’s books does not raise the kind of questions Ahmed considers in the context of post-coloniality, it is, like Ahmed’s mediated. I come to Hall’s books through a kind of translation not very dissimilar to the one that allows Ahmed to encounter Devi’s text in English (Spivak’s translation). This is not a translation into another language, but one, nevertheless, which makes Hall’s work accessible to a wider audience, including myself working in Britain: I am referring to the award-winning exhibition catalogue *Holding In, Holding On*, and to the film *I Make Books*, from which the second epigraph of this section is taken. The former reproduces excerpts taken from Hall’s books (though unmarked, as the same font is used throughout), together with photographs; the latter allows a more faithful, three-dimensional view of the books, but can only simulate the process of turning their pages:

And so I face this text in writing about it here. I must respond to it. But in responding to this text, already mediated by the failed proximity of translation, I cannot fully face this text, I cannot transform the text into a face. I miss it. But my missing of it, my failure to face up to it, is also an encounter with it, and engagement with it, and a responsibility for it. (Ahmed 148)

As Ahmed is right to suggest, “[o]ne’s infinite responsibility begins with the particular demands that an other might make,” but cannot stop there (147). If the particularity of my response to Hall, mediated by the catalogue and the film, cannot fulfill my responsibility, rather than seeing this as a form of failed witnessing, I prefer to approach it as “a call, a demand, for a future response to an other *whom I may yet approach*” (Ahmed 146, emphasis in the original). I hope this essay performs a particular and finite engagement with Hall’s artists’ books while also gesturing towards an approach that is “yet to be taken.”

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“Lessons to Learn”: Constructions of Femininity in Popular Magazine Breast Health Narratives

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Abstract:

Personal narratives associated with breast health are prominent in women’s magazines. Within the personal stories are themes and frames that reinforce traditional femininity, support narrow beauty ideals, and emphasize women’s roles as mothers. This article analyzes personal narratives about breast health published in the October issues of forty women’s magazines from 2005 through 2008. Feminist theorizing about breast cancer grew out of the women’s health movement which recognized that paternalistic thinking and scientific discourse have worked to disassociate women from knowledge about our bodies as a form of control. Breasts have social and cultural significance related to motherhood and sexuality, which additionally complicates the discourses surrounding breast health. Magazine content related to breast health is created and produced within a cultural context that devalues women. Building on a critical analysis of personal narratives about breast health this article argues for a more nuanced understanding that recognizes the potential for empowerment that the inclusion of women’s lived experience provides while being critical of narrow gender constructions supported by mainstream breast health narratives.

1 In October, which is designated Breast Cancer Awareness month, popular U.S. women’s magazines contain numerous articles, advertisements, and special features about breast health. The most prevalent format is the personal narrative. Feminists have long advocated for the inclusion of women’s lived experience, and published personal narratives about breast health have the potential to give voice to a variety of women’s¹ experiences. However, magazine content related to breast health is created and produced within a cultural context that typically devalues women. Within the personal narratives are themes and frames that reinforce traditional femininity, promote narrow beauty ideals, and support a potentially essentialist understanding of women’s roles as mothers. Building on a critical analysis of personal narratives about breast health I argue for a more nuanced understanding that recognizes the potential for empowerment that the inclusion of women’s lived experience provides while being critical of narrow gender constructions supported by mainstream breast health narratives.

2 Feminist theorizing about breast cancer grew out of the second-wave feminist women’s health movement, which recognized that paternalistic thinking and scientific discourse have worked to disassociate women from knowledge about our bodies as a form of

¹ It is important to note that men can and do get breast cancer. However, since the focus of this analysis is on representations of breast health in magazines aimed at women, I will limit my discussion here to women and breast health.

control. Breasts have social and cultural significance related to motherhood and sexuality, which additionally complicates the discourses surrounding breast health. Several feminist works deconstruct the medical and mediated discourses of breast cancer to show how they are both influenced by and serve to influence perceptions of women's bodies (Lorde; Sedgwick; Kasper and Ferguson). In her article on the mainstream rhetoric of breast cancer, Susan Yadlon states "breast cancer discourse not only emerges from ideological assumptions but performs cultural work as well" (645). Feminist media critics have analyzed the importance of the media in creating and maintaining stereotypes of femininity (Kilbourne). Media are important sites for creating "representations of the social world, images, descriptions, explanations and frames for understanding how the world is" (Hall 90). Many of the breast health articles and images intentionally and unintentionally reinforce gender stereotypes.

3 Contemporary narratives of breast health should be understood within the context of the history of published writing about breast cancer. Written references to breast cancer appear as early as Egyptian papyrus (Lerner). Until the 1960s the majority of the published writing about breast cancer came primarily from the medical field. In the 1960s some women, mainly outside of the medical field, responded to marginalization caused by the prevailing medical philosophies of breast health by writing and publishing their own experiences. Many of the published narratives focused on providing other women with information about negotiating breast health concerns. The new narratives of breast cancer questioned surgeons' authority, revealed the uncertainty regarding treatment effectiveness, and questioned male doctors dictating to female patients. Doctors and many patients did not easily accept the philosophy that breast cancer treatment should be decided by personal choice. Surgeons who were not used to having their authority challenged were not happy to be confronted by patients who had read about breast cancer in a magazine or popular press book. However, women's personal narratives related to breast health resonated with the readers of women's magazines, and they became an established and prominent feature.

4 Women-focused print magazines remain a prominent source of messages and images regarding breast health. Numerous studies have documented the importance of popular media outlets as a source of health information (Moyer et al.; Metsch et al; Covello and Peters). Henderson and Kitzinger found that women often used the media to explain or justify their analysis of breast health. In a study of preferences for receiving breast health information among Hispanic women age 35 or older, Oetzel et al. found that some women actually preferred mass media outlets to expert sources. However, the traditional print format magazine is struggling and in the midst of major changes. Despite challenges to traditional

magazine publishing and encroachment by electronic sources a 2005 Kaiser Family Foundation Poll found that 64% of the respondents had used print magazines as a source of health information in the past 12 months. In a study published in 2008, Tian and Robinson found that the Internet is not simply replacing traditional media channels such as magazines as a source of health information, rather that both sources are being used and most often in a complementary fashion.

5 This analysis examines articles and special features about breast health that appeared in U.S. women's magazines October issues in 2005, 2006, 2007 and 2008. The magazines selected includes magazines aimed at older women (*Good Housekeeping*, *Ladies Home Journal*, *Redbook*), younger women (*Glamour*, *Self*), women of color (*Ebony*, *Essence*, *Latina*), lesbians (*Curve*), and general women's audience (*O: The Oprah Magazine*, *Real Simple*). In total forty-four magazines were reviewed to identify articles about breast cancer. The articles were read and coded based on coding categories developed from previous research and a review of the literature. Articles were considered to be personal narratives if the main focus of the article is people's lived experience with breast health. This includes autobiographical pieces as well as articles told to professional writers and articles written by friends or relatives. A total of thirty-two articles were included.

6 There are narratives about: breast cancer survivors; women who died of breast cancer; and relatives and friends (including celebrities) of people with breast cancer. The stories invoke a range of emotions and deal with a variety of issues related to living with (and less often dying from) breast cancer. Some of the personal stories are funny, others are sad, and some take the readers through a rollercoaster of ups and downs related to dealing with a serious illness. Other narratives are celebratory or self-effacing. There are many that are intended to serve as cautionary tales. Individually the narratives encourage women to speak up and be heard, while collectively the narratives serve to reinforce the social construction of gender in ways that are often narrow and confining.

Motherhood

7 Motherhood appears in twenty articles. The articles and images address motherhood, mothers, and mothering in a variety of ways. The representations include images of pregnant breast cancer survivors and survivors who struggle with fertility and adoption. In this context motherhood becomes something that is more difficult because of breast cancer but is eventually achieved. "We conceived my daughter naturally less than a year later. It was truly miraculous" (Mantica 166). The emphasis on the impact of breast cancer on fertility

reinforces the representation of younger women with breast cancer. Post-menopausal women are at higher risk for breast cancer but magazine coverage of breast cancer places an emphasis on younger women.

8 The presence or absence of mothers with breast cancer is another common theme. The focus of these articles is typically how celebrities have learned from their mothers' experiences and have become advocates supporting breast cancer awareness and activism. In *Daisy, Tell My Story in Public*, celebrity Daisy Fuentes talks about her mother's struggle with breast cancer and how it changed her close-knit family for the better. Fuentes uses this opportunity to call for "more research funds and free mammogram screenings, especially in low-income communities" (Greeven 128). In another article, actress Judy Reyes explains that she learned from her mother's experience with breast cancer to "question everything and do your research" (Romero 124). These celebrities who have been impacted directly by breast cancer are using their celebrity status to increase breast cancer awareness.

9 Articles about motherhood and breast health contain stories of women who are struggling to be good mothers while taking care of their own health. In "Two Sisters with Breast Cancer: One Made it. One Didn't," April Zemla describes visiting her sister Norma, who is suffering the effects of chemotherapy: "Her kids were unfed and running wild around the house, but she couldn't do anything about it. It broke my heart" (Shepelavy 319). A decade later when Zemla is struggling with a personal breast cancer diagnosis taking care of her own children proves difficult. According to the article, "she caught herself neglecting them as she struggled with the first wave of insurance forms and doctor appointments" (319), and as she went to bed later that night she chastised herself for not making the most of the day and spending time playing with her children. For Meka Flowers one of the most difficult parts of dealing with breast cancer was the reality that she could not pick up her two-year-old daughter, and there were times when she could not do certain things with her daughter (Green 138). This subset of narratives may serve to reinforce cultural pressures that are placed on women in relation to parenting.

10 Occasionally there are narratives that work to relieve some of the societal emphasis on being a "perfect mother." Rene Syler, who underwent a prophylactic mastectomy because both of her parents are breast cancer survivors, wrote a book that is designed to "take the pressure of mothers who find themselves stressed out and stretched thin in their efforts to be supermoms" (SekouWrites 158). Her book strives to give women permission to accept good enough rather than some idealized notion of perfection when it comes to mothering. She emphasizes that children need time, love, support, and attention.

11 According to the women in the narratives, breast cancer can serve to refocus the importance of being a mother. Hilene Flanzbaum states that “having breast cancer focuses me on my children like a laser” (228). Other moms talk about how their children help them to deal with breast cancer: “My girls make mustaches with the hair at my feet. It doesn’t seem so awful” (Corrigan 218). In these and other narratives the difficult realities of living with breast cancer are tempered by the joys of being a mother.

12 Motherhood and mothers are also talked about in the context of genetic risk. In the article “My Mother, My Cancer Fears,” Sara Austin comes clean about the reality that instead of making her more proactive about breast health, her mother’s experience paralyzes her into avoidance. She calls for more attention from the medical community to women’s fears. Other women try to keep their mother’s breast cancer in perspective: “I get my tests, try to love my body and free myself from stress. Just because my mother got breast cancer doesn’t mean I will” (Bried 142).

13 Another theme related to motherhood is about helping children to cope with cancer. In the essay “My Third Lung,” mother Laura Walsh Plunkett explains allowing her daughter to play Dr. and examine her as part of the daughter learning to cope with her mother’s breast cancer (130). Maimh Karmo refused to keep her baldness from her three-year-old daughter. Her daughter was originally shocked but grew to love her mother’s baldhead, and she learned to view her mother’s returning hair as a sign of wellness (Green 140).

14 This emphasis on motherhood is potentially essentializing. Feminists have long acknowledged the challenges of recognizing women’s biological differences while trying to advance gender justice. While motherhood could possibly serve as a point of collective action, it more often is taken up as a nexus of familial connection. Women may feel pressure from society to be mothers or even “supermoms” in ways that men typically do not. Traditional notions of femininity dictate that even women who are dealing with life threatening illness place the needs of family before taking care of themselves, as expressed by Angela Agbasi: “the best way to take care of me was to take care of my kids” (Welch 218). While the articles often acknowledge the dangers of this behavior they do little to present solutions.

Sex and Sexuality

15 The personal narratives present a complicated picture of sex and sexuality in relation to breast health. Breasts are sexualized in mainstream media. Many women relate to their breasts sexually. Many of the narratives detail women’s struggles with body confidence post-

treatment. “I felt embarrassed to show him my breast, which after my partial mastectomy looked caved in” (LaRue 194). The women in the narratives are challenged to be comfortable with their bodies in a culture that often overemphasizes breasts.

16 The article “The Story Behind the Scar” is about how women adapt to their post-treatment bodies and includes women who made a variety of choices. For several women breast reconstruction was a vital part of the healing process. In speaking of her reconstruction, Beth Silverman states: “[...] the surgery gave me back a piece of my womanhood that cancer took away” (Mantica 169). Kathy Burgau “finally felt whole again” once she had completed her breast reconstruction (Mantica 166). However, for Melissa Pantel-Ku a double mastectomy without reconstruction was the right choice: “who would have imagined that I would feel more like a woman when I was stripped of my breasts” (Mantica 170). These narratives echo the complicated relationships most U.S. women have with breasts. By presenting a range of women who were satisfied with a variety of options this article works to potentially empower other women as they make choices about their breast-cancer treatment. The accompanying nude images present a range of post-treatment breasts and largely serve the purpose of exposing breast cancer.

17 “Daring to Date Again” is a brutally honest exploration of the challenges of dating and sex as a person living with breast cancer. Stephaine LaRue who was diagnosed with stage IV metastatic breast cancer at age 33 and given a year to live talks about how her sex drive went through the roof during her treatment. For LaRue “the sex was lifesaving; it helped take my mind off everything that was happening” (193). She is able to have satisfactory sexual relationships despite her illness. LaRue advocates for other breast cancer survivors particularly when it comes to talking honestly about sex: “[...] it is extremely important for oncologists to be open about sex with breast cancer survivors” (194). She believes that sex can be healing and sees orgasms as part of her therapy. Narratives such as LaRue’s are an important part of being honest about women’s lived experience with breast cancer.

18 In “Our Marriage Fell Apart When I got Breast Cancer,” Marie talks about the impact that her breast cancer treatment had on her sex life. “The treatments took a huge toll on my appearance, but worse they also caused our sex life to fizzle” (Hanson 198). Marie’s sex drive plummeted. Her husband mourned the loss of her breasts and told her he was no longer attracted to her and didn’t want to stay in a sexless marriage. Angry, Marie tells him to explain to everyone why he was leaving and then leave. But rather than breakup they decide to work with a therapist. The article includes analysis from the therapist who helped the couple work on their marriage by reconnecting as a couple and focusing on who they are

today. This article acknowledges some of the challenges that breast cancer treatment poses to feeling confident and sexual. The treatment can have physical effects (scars, nausea, vaginal dryness, swelling, and body changes including loss of breasts and hair), which can impact sexuality. In addition, the emotional effects (fear, depression, and anxiety) can also impact sexual relationships. The inclusion of narratives about the intimate details of post-treatment sex can be helpful to women who are making treatment decisions as well as to women who may be suffering like Marie.

19 Personal narratives about breast health in mainstream magazines are overwhelmingly heterosexual. Only one article, a feature about Melissa Etheridge, mentions a lesbian relationship. The four issues of *Curve* magazine (a magazine aimed at lesbians) examined for this analysis did not contain any personal narratives. Lesbians have been medically underserved and are often marginalized in mainstream medical settings because of institutional homophobia. In addition, lesbians are less likely to have routine visits for birth control and prenatal care, where much of the standard screening is done. The lack of personal breast health narratives by or about lesbians is detrimental.

Beauty Ideals

20 In her 1980 publication *The Cancer Journals*, Audre Lorde argued that by erasing the visible effects of breast cancer we isolate women who might rally together to fight collectively. In the last three decades breast cancer has become more visible. With an organized movement, women and men have successfully fought to change the ways that breast cancer is understood and treated. Breast cancer activists have been successful in bringing a great deal of public attention to breast health. However, the images and narratives about breast health that appear in popular magazines often intentionally and unintentionally reinforce traditional beauty norms. The text and accompanying pictures place an emphasis on women's looks. Granted, many of the articles come from women's magazines with a decided focus on beauty; unfortunately the result is that women are encouraged to privilege looking good over being healthy.

21 Social pressures complicate beauty discussions within the breast health narratives. Women are expected to conform to a narrow ideal even while dealing with a potentially deadly illness. The effects of breast cancer treatments can include loss of breasts and hair each of which can have social and cultural significance related to femininity. Through out the narratives women talk about how these changes impacted their lives and how they dealt with the new physical and emotional realities. In the article "We Beat Breast Cancer," Meka

Flowers states: “When people see that you don’t look a hot mess, that shows you are not letting it get the best of you” (Green 138). For Flowers conforming to societal beauty norms is part of controlling her cancer. Robin Roberts, a *Good Morning America* anchor, shared her breast cancer experience with the television audience. But even though she was very open about her experience, her position as television personality required her to present culturally prescribed femininity. Her treatment made it difficult, because of many changes to her body. In speaking about the challenges her cancer posed for the show’s makeup artists, Roberts states: “It was like putting Humpty Dumpty back together again every morning” (134).

22 Loss of hair is talked about in many of the articles. The moment when Lynda Gorov shaves her head (in response to hair loss from chemotherapy) is a key part of her narrative. The reality of living with a baldhead is complicated by the response of others. When Gorov wraps her baldhead in a scarf, “they seem to see sickness. They see their greatest fear dining at the next table” (127). However, when she does not cover her head the response is very different: “I like to think it says ultra-hip avant-garde performance artist who could kick your butt” (127). In this way, Gorov is able to subvert the pity she hates. She enjoys projecting an image of strength. For Regina Stuve hair loss was the most emotionally difficult part of coping with cancer; “it was even harder than not breastfeeding” (Gurwitt 180). She does cope by wearing specially made baseball caps (with hair extensions attached) and joking that she has the same hairstyle as her infant son. Many of the narratives about hair loss also serve to disrupt traditional beauty norms, such as when Roberts relates the story of modeling in a televised fashion show without her wig. “I held my bald head high and strutted my stuff” (134). The accompanying picture of Roberts shows her bald on the catwalk. The image of a woman who is bald and beautiful has become a symbol of strength and survivorship.

23 The article “I was Diagnosed at 26” is about breast cancer survivor Allison Briggs who documented her experience with a camera and posted the pictures on a website. In one accompanying image Briggs is wearing only a pair of jeans. One arm is suggestively covering her breasts and she is looking out at the camera in a sexual manner. Briggs describes the picture as “while I still had my breasts and some hair” (316). So this pre-treatment picture is an image of the “old” Briggs. But the image of a topless, young, thin, white, and blonde woman in a suggestive pose reinforces the narrow representation and sexualization of women in breast health magazine articles.

24 It is common for women to have difficulty negotiating the balance between mourning the pre-treatment body and celebrating a new life as a survivor. Many, like Allison Briggs, learn to reframe what it means to be beautiful: “I used to associate hair, nails, eyelashes and

breasts with beauty, but when I lost them all I truly felt more beautiful than ever simply because I was alive” (317). Collectively the breast health narratives emphasize women’s looks. While the narratives may recognize and promote new beauty norms, there is still an underlying current that women should focus on looking good and seek external validation of their looks.

“Lessons to Learn”

25 The theme that surviving breast cancer presents an opportunity for learning important life lessons permeates many of the narratives. Melissa Ethridge explains that she was jolted by her breast cancer diagnosis: “I thought I was being good, eating right, exercising. But this was the road I was going to have to go down. Maybe kicking and screaming, but this was my new path. I knew there had to be lessons to learn” (Glock 98). Maimh Karmo states that “it was the best time in my life because it gave me the opportunity to really live” (Green 140). Because of her breast cancer experiences she learned, as she says, that “I’m stronger and more powerful than I ever thought I could be” (Green 140). These sentiments can potentially serve to empower women.

26 Breast cancer also serves as a catalyst for women to change how they are living their lives. Helene Flanzbaum boldly declares: “Having breast cancer changed my life—for the better” (228). Clarification led to action for Flanzbaum who “stopped sleepwalking through my days. I started paying attention” (228). The same sentiment is echoed by Melissa Ethridge “My work, certain friends, anything that was taking life away from me, I cut out. I looked at my cancer as a metaphor. I examined my whole life to find what was cancerous, and I cut it out” (Glock 100). For these women, breast cancer, while grueling and physically difficult, was also life affirming.

27 However, this emphasis on viewing cancer as being part of an important life lesson can be a challenge for women who are not feeling positive about the experience. As Oni Faida Lampley states: “There was a ‘right’ way of having cancer, and I was doing it wrong” (164). In addition, the prevalence of narratives that reinforce positivity may inadvertently serve to blame women who ultimately succumb to breast cancer, as stated by Lynda Gorov, “as if only pessimists drop dead of disease” (128). Expecting a positive outlook in the face of disease may also be gendered. Some of the pressure put on women with breast cancer may reinforce cultural ideologies about “good women” being cheerful and not making a fuss.

Conclusion

28 New femininity as presented in breast health articles requires strength, grace, and beauty (even if the definition of beauty has to be rewritten) while dealing with breast cancer. These narratives are overwhelmingly stories of ultimate triumph (with stories of survivors outweighing stories of women who die from breast cancer). Feminist theorists of popular culture recognize that in addition to dominant ideologies media messages can also be resisted or understood in oppositional ways. So while breast-health narratives from popular magazines largely serve to support and maintain traditional gender norms, they also give voice to breast-cancer survivors. Individually and collectively these breast-health narratives present a picture of women's lived experiences. In addition, the presence of so much information in a popular format has created social and medical change surrounding breast health. But there is still much work to be done.

29 While there currently is a great deal of public attention surrounding breast health, much of that attention has been focused on viewing breast health as an individual issue. Breast cancer has social and medical dimensions. It is important to recognize that breast health is both an individual and a societal issue. Popular narratives allow space for the inclusion of women's lived experience with breast health, but it is crucial that a greater diversity of women be represented. Young and middle-aged white women are prominent. African American women are well-represented (in both general-audience magazines and magazines aimed at women of color). There should be increased representation of Latina, Asian American and American Indian women as well as women from other ethnic groups. In addition, there need to be more narratives from a wider range of sexual orientations; women over 50; poor women (with a critical analysis of the impact of poverty on health care); and trans-women. Specifically more narratives need to challenge traditional ideals of femininity. Increasing the range and diversity of women's experiences represented in popular narratives of breast health would increase the potential for women's empowerment.

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The Case of the Missing Areolae: Race and Breast Reduction Surgery

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Abstract:

Writings about female breast reduction surgery have primarily focused on the size, location on the chest, and the techniques for such surgical reduction. Few have looked at how the areola is handled, nor whether there is an underlying racial context in decisions about this part of the female body. This multi-disciplinary, multi-technique, part analysis, part auto-ethnography seeks to open up and broaden the discussion, asking the question whether subliminal racial preferences play a role in surgeons' decisions.

1 Writing about female breast reduction surgery brings to one's attention ideas about possibilities and desirabilities. Yes, surgery means cutting the body, but to "reduce" through cutting requires some thinking through. What is being reduced, materially and non-materially? Obviously the size. Also the content, yes? The content of what? The outer visible thing we call a breast, yes. Also tissue, etc. inside. But is there also something else being reduced? The woman's sense of who she is? Or is that being expanded? And then there is desire. Whose desire is it that goes into play when a woman opts to have surgeons reduce her breasts, especially when there are deep, continuing questions about female agency? When historians, feminists, and physicians, as well as writers in popular magazines, write about breast reduction surgery on the female body, they vacillate about the surgery's desirability. Varying and sometimes conflicting perceptions of patients, surgeons, and the health insurance industry all weigh in. Not having devised a truly objective method to define an "overly large" breast, the insurance industry has weakly made a stab at clarity and specificity post hoc, so to speak, by allowing payment for the procedure only in the event of removal of a fixed percentage minimum amount of tissue, while giving secondary consideration to the affective complaints of patients. With regard to surgeons, whether female or male, considering the many cultural fixations about breasts, especially in the West, the impossibility of any objectivity on their part seems clear.

2 After all, what are breasts of a size more than flat but the primary indicia of the female sex? To therefore suggest that it is possible and even desirable to reduce this obvious sign of being female points to ambivalence about being female and ambivalence about femininity itself, individually and collectively.

3 *Admittedly, she now comes to be aware of having had, after the fact, a great amount of personal conflict about those things on her chest. Why did she have them "reduced"? Oh, yes, she trotted out the requisite list of complaints, all true, about bra straps slicing into her*

shoulders, back pain, a constant sensation of being constantly pulled forward and down by the weight of those boulders on her ribs. Two sacks of potatoes like albatrosses around her neck. Then, of course, but at the least, the gaze of male eyes towards a point below her neck infuriated. But are there layers of some vague murmurings beneath as she tries to diminish male power over her existence by shrinking her awareness of the focus of their attention—away from her intellect?

4 In examining female breast reduction contextualized by race, I will touch upon the act of this particular kind of surgery, the motivations for performing such surgery, on the part of patients as well as on the part of surgeons, and the unquestioned agendas in the development of choices by surgeons in performing and developing new techniques.¹ Do the motivations, the development of choices, and the acts interlock with racial ideas? We are accustomed to consider the breast in toto, with perhaps momentary attention paid to the nipples for nursing or sexual reasons, our attention driven by the male focus.

5 But there's one feature that usually gets ignored and that is the areola. Are there extensive perorations on areolae in newspapers, magazines, and billboards as there are on breasts and nipples? No. How many women even know the word? How aware are women, in preparing to have a knife put to their bodies, of what's hidden in everyone's ideas about human breasts?

6 As a start, finding resources on the topic of female breast reduction is difficult. This complexity contrasts with numerous references and citations to breast cancer, as well as to breast augmentation. It would appear that a continuum of perception of need exists.

7 So, Trinh Minh-ha declares, *"to seek is to lose, for seeking presupposes a separation between the seeker and the sought, the continuing me and the change it undergoes"* (*"Not You / Like You"* 371). However, in order to be with the reality of the surgical cutting away of a specific part of her breasts, the areolae, she must seek in order to gain, go back to her center, realizing that even so, with their loss, she has not lost. Taking up this quest for her areolae, to which she had no awareness of attachment before they were taken without her consent, has opened her up to layers deep within which now peel away, slowly, as she thinks, writes, stops, puts aside the writing for weeks, months, consults with others, live and on pages, goes back again, thinks some more, not digging, not tapping, as it's all there already waiting for her readiness to face the loss as gain.

¹ In carrying out the research for this paper, I found the use of both "mammaplasty" and "mammoplasty" in the titles and text of books, articles, and on Internet sites. When quoting and referencing, I will retain the spelling the writer used. However, in my own comments, I will attempt to maintain the use of "mammaplasty," thereby retaining the root "mammary."

8 At one end of the continuum is breast surgery for breast cancer. At the other end are procedures for breast augmentation. In the middle at an unfixed place breast reduction surgery quivers. Its place wavers as a result of conflict about whether this procedure results from vanity, therefore putting it under the rubric of “cosmetic surgery” thus closer to the site of breast augmentation, or whether this procedure is “medically necessary” putting it closer to the situation of breast surgery for cancer.

9 *This whole discussion about being in the middle really bothers her, as someone who’s so tired of attempts to fragment her whole. Having her breasts sliced down seemed an effective way to internalize erecting that middle finger at the universe, unaware. But why breasts, since they seem more clearly markers of female-ness rather than race markers? Or was she missing something?*

10 Looking at the conflict over the procedure, having to tease out articles relating to breast reduction is bloody frustrating. Here again male domination of the agenda in the so-called objective paradise of scientific research makes the skewed appear the norm. They make her work extra hard, yet again, to get to a place where she wants to be, which is other than flat on her back, except as an act of power.

16 *And then, there are the areolae, those coins or circumambulating talismans of darkness around the nipples, forming a broad, supportive shadowy bridge of in-between-wholeness between nipples and fleshy anxiety. Before the surgery, she gave them little attention except to note out of the corner of her consciousness that they seemed larger, more spread out, covering almost half of each breast, than those of the pale pink women at whose breasts she slipped a glance in the locker rooms. She was more focused on the weight and intrusion of these things that seemed determined to stifle her, when she was lying down, on her chest, on her side, on her back, when she was standing, when she was running, when she was lifting weights, every second of her material existence.*

17 Anecdotally, on my expressing my concern about the possible implications of my research, in that I feared that there also I would find evidence of racism, a physician friend, who is Jewish, told me that he dated black women from Africa, from the U.S., as well as white and Jewish women, and he never noticed any race-based difference in breast size or size of the areola.²

18 *Well, maybe he was not looking. Or maybe he could only see areolae of a size correlating with what he expected to see. Maybe the larger areolae were invisible to him.*

² Telephone conversation, December 9, 2005.

19 Gilman definitively states that the “breast functions as a racial sign even in the basic aesthetic surgical guides to breast reduction” (232). Ample evidence exists, as presented by Haiken and Gilman, of the surgical creation of northwestern European noses on black and Jewish patients and of Northwestern European eye shapes on Asian patients, both at the request of the patients and at the hands of surgeons helping patients to appear more ideal, more civilized, more pleasing, more “Western,” more beautiful, or perhaps to try to escape the restrictions of their cultures. Either they’re reacting to the outside world looking at and judging their physical presence or it’s their own world jumping on them. Or both at the same time. I came across no evidence that in changing noses or eyes, information about specific changes that were to be made was not shared with the patient, as was the case with this particular patient and her areolae.

20 My research uncovered no unequivocal statements about the presence of race-based ideas in determining what the post-surgery breast areola should look like. To claim that the areolae “should” be reduced in proportion to the breast, I ask why, and who determines what that proportion “should” be. Therefore, I hypothesize that the resulting areolae in breast reduction surgery embody race-based notions about the “ideal” breast.

21 *Browsing through the photos of breasts in Spiegel and Sebesta’s Breast Book (2002), she tries to remember her breasts pre-surgery, and she wavers about agreeing with Gilman that the areolae are larger the closer to the equator you get. In the photographs, the areolae of indigenous women of the Americas or the South Pacific seem no larger than those of their Aryan sisters of the north. Perhaps, like my physician friend, the photographers unconsciously aimed their attention only at breasts that had smaller areolae, as being the more beautiful breasts. Still why were her breasts and some breasts, and not even the darkest of breasts, sporting areolae covering almost one-third of the breast? Spiegel and Sebesta write that the areolae, along with the breasts, expand during pregnancy and retract after (53). Are women of the tribe of larger-sized areolae in a permanent psychic state of pregnancy, even if they never give birth to a human? What are they pregnant with? Was her drive to reduce her breasts a revolt against being quick with the unknown?*

22 When medical culture and the public both came to the conclusion that breast reduction resulted in a decrease in physical, not just psychological, symptoms, this type of surgery came to receive more acceptance. That a woman would choose to undergo what in essence is major surgery must speak to her perception of her situation as being desperate.

23 Since this type of surgery increased in acceptance over the years, why is it still so difficult to find research articles that focus specifically on that type of surgery? Over time,

one perceives a shift from “worship of breasts to domination of them” (Spiegel and Sebesta 53). One comes to understand the conflicted feelings that individual females and males, the medical establishment, the health insurance industry, as well as popular culture have about female breasts. Female breasts have been a focus for anxiety for a very long time. Combining anxieties about race with anxieties about female breasts leads to the inevitability of pathological projection.

24 Men are anxious about women’s breasts for reasons of sexuality, procreation and survival of their genes. As an effect of patriarchy, women are anxious about their breasts because men are anxious. An important way for women to survive is for men to have less anxiety about women’s breasts.

25 Who has control over female breasts and for what reason determines both their perception and handling. Early on, any removal or reduction of the female breast could be associated with the acquisition of power by that woman. On the other hand, the Medieval standard for beautiful breasts was that they be small, round, firm and wide apart. These breasts, as objects of male desire, were always white and often compared to two apples (Latteier).

26 *Apples tend not to have large dark circles around their point of attachment to the tree unless they’re diseased or rotting.*

27 This early preference by white males regarding the desired appearance of white female breasts may be so deeply rooted as to be embedded in the choices that surgeons currently make when crafting new breasts during breast reduction surgery. For example, in an article describing what’s purported to be an improved technique in breast reduction surgery, the clear objective is to achieve “nipple projection,” with no rationale given for why this is a desirable outcome (Casas et al 955-60). A “boxy” breast mound and “deficient breast projection” are put forth as outcomes to be avoided, as the goal is “conical breast shape” and “anatomic projection.”

28 Why is it that, as female breasts increasingly came under the control of men, ideal female breasts must be for pleasure, look like apples (first small, later large), and be high on the chest, of adolescent placement and form, simultaneously with being too large to be adolescent? The standard for perfection is contrary to nature, unrealistic, and impossible to achieve, without repeated surgical, and thus male intervention, since most surgeons are still male. Even with the increasing presence of female surgeons, white males control the text.

29 *Using the metaphor of “text” troubles me in writing about a topic so intimately personal to females. Leonard Shlain posits that “the demise of the Goddess, the plunge in*

women's status, and the advent of harsh patriarchy and misogyny occurred around the time that people were learning to read and write" (viii). *With patriarchal mores so internalized, I struggle to find a less masculinist metaphor.*

30 If Diana Jones accepts that women tend to view their own body, in terms of their breasts, through the lens of men's perceptions, it would appear that she accepts as uncontroverted fact that women are disempowered when it comes to their breasts. If this is the reality of women's relationships with their breasts, then issues of power and disempowerment lie at the core of the history of how women's breasts are perceived, touched, manipulated, and thus affect decisions about reduction. As Kathy Davis puts it, "[t]he body remains [...] a text upon which culture writes its meanings" (50).

31 Jones counterpoises contrasting views the dominant white male culture has held of white female breasts vis-à-vis black female breasts. Her comments on the "mammy" figure in U.S. history serve to validate the perspective of female breasts as objects of production, primarily in those of the lower classes, which here included virtually all people of African descent in the U.S. during the 18th and 19th centuries, regardless of their economic status, even if they were not enslaved. Being objects of production in a capitalist culture, the larger the better. In addition, the larger the breast the closer its owner is to the primitive.

32 *She pauses, stops at this word "primitive," although it's painful to do so. So many, many layers of generations of trying to wash every trace, eliminate the slightest hint of being associated in any infinitesimal way to the "primitive."*

33 *"Child, why can't you keep your hair tidy? It looks so wild," says a proud wavy-haired aunt married so comfortably to a Jewish Lebanese Jamaican with dead straight hair, straight nose, and blue eyes. Their skin color is the same. Everyone's skin color in the room is the same, but still there's a difference.*

34 *With her two hands, she palms the little girl's hair hard down onto her skull. She felt that she couldn't breathe, she couldn't see. She was suffocating, dying. Don't be wild. Don't be female. To be female is to be uncivilized.*

35 A battle rages on our chests. Salvos of insults, leers, obsessions land on the two mounds on that terrain. The female breast being contested territory, a page upon which is written conflicting text, plays an important role in any interpretation of breast reduction techniques, choices, and developments. One way to decrease the warfare is to shrink down the mountains, less territory to fight over, less soil on which to plant the flag of possession.

36 Using the metaphors of "text" and "territory" to represent female breasts troubles me. Perpetuating this perspective seems highly suspect in any effort to resist the oppressive hand

of patriarchy. Alternatives for communication exist. However, academia has fixed on text as the ruling medium of messaging, which then itself reifies and reinforces patriarchal domination. I see no way of feminizing “text” or “territory.”

37 *The terrain remains contested. Uncle G, the husband of one of the aunts, announced to the world that his wife’s breasts were like that of an aircraft carrier from which one could launch fighter planes. She felt disgusted, wanting to have nothing to do with any of them. But she has no choice, no say in the matter. She is just a child, and a female child at that.*

38 When women take the message of responsibility for their breasts to heart and seek breast reduction as a means of exerting control over their “out-of-control” overly large breasts, they are prodded and questioned and have to pass tests and rules of thumb. Furthermore, as a result of over-emphasis on the possibility of breast cancer, “being a woman with breasts has come to be defined as a risk factor” (Davis 50). No matter which path you take, the place you get to is that being a woman is risky.

39 *This she knew all along. This came at the time of her birth, even before that, at the time of her conception. The message drummed into her mind from time before time, is that being female is deadly.*

40 Women are set up for an impossible conflict. They are to protect this part of their body, which does not really belong to them, but when that body part becomes diseased, it can kill them. So something they are told is not part of them in life becomes part of them in death. Therefore, opting for breast reduction surgery can come to be interpreted as fiddling with a time bomb or messing with property that does not belong to her. Breasts belong to men. They signify femininity. Within the patriarchal hetero-normative world-view, femininity exists only for the pleasure of men. Whether lesbian women view female breasts differently than men do is not within the scope of this essay. Breasts belong to men in their role as sexual beings and also as members of the medical establishment when breasts became medicalized. Finally, breasts also belong to men because it is men who, in general, and with their medicine, exert control over the discovery, diagnosis, control, and removal of female breasts when cancer comes into the picture. And when cancer comes into the picture, patriarchy still retains control, burning or removing the breast(s) not to empower the woman, as was done for Amazons, but in an attempt to maintain her now disempowered existence in a culture, where, breastless, she is no longer feminine and therefore no longer of value.

41 It, therefore, should come as no surprise that when a woman seeks to exert property rights over her breasts, to right/write her own life, by seeking breast reduction surgery, the culture seeks new and additional ways to remind her that she does not and cannot ever have

control over her breasts. Her breasts belong either to men and/or to medicine. With both men and medicine in the U.S. being nurtured in the Anglo-Saxon cradle of cultural ideas, so too must women's breasts be held to the Anglo-Saxon idea of the perfect.

42 *Yes, I realize I continue the materialistic metaphor of territory, in the grip of metaphorical thinking. Doing so, I aim to meet the other where he stands, in a frame within which he feels comfort, before shape-shifting him to another place of being so as to be with her where she and her areolae have their real existence. "It is our human condition to be unable to escape the dimension of the Symbolic" (Davoine and Gaudilliere 68).*

43 In writing about breast reduction and decisions about how to handle the details of the breast such as the nipple and the aureolae, the issue of choice dominates, as a result of the need to frame the entire discussion within the context of one of contested power, because of the reality of the domination of patriarchal concepts. On the one hand, what seemed of most importance to surgeons was developing techniques to reduce the amount of scarring as well as developing techniques to maintain as much as possible of sensation in the breast, especially in the nipples. These objectives would seem in the interest of the women themselves, albeit also in the interest of the men or women with whom the woman might be having an intimate relationship. On the other hand, nipple projection, as mentioned earlier, as well as high placement on the chest and conical shape, are also important objectives to the surgeons. These objectives seem less focused on the best interests of the women as individuals and more focused on the interests of the culture, and of male needs, conditioned by culture. But nowhere in all the research articles on breast reduction surgery was there any discussion or debate about the size of the areola, except with a brief mention about proportionality. However, more recent websites of breast surgeons and clinics at least briefly mention the desirability of the woman discussing areola size pre-surgery with the surgeon, while often making the assumption that the cause of a larger areola (from the perspective of the surgeon) results from the stretching involved with the larger breast.

44 *None of them checked with her younger sister who has natural size B breasts with aureolas half the size of the breast, not this tiny darkness around her nipples that she got after surgery.*

45 When it comes to determining how much of the areola to remove, I conclude that clear cultural and racial influences play an important role, as a result of embedded cultural definitions of beauty. A breast with more areola tissue than found on a European or Asian breast is deemed undesirable, if not ugly. To increase the desirability of that breast, the size of

the areola must be decreased, in an environment of almost total silence about that decision. Is it because the areola is always darker in color?

46 The use of the word “freak” by more than one young woman narrating her travails with her large breasts validates Gilman’s comment that the “abnormality” of large breasts consists of “being seen as different within the model of the racialized (or primitive) body. Women with large, pendulous breasts are not yet ‘New Women’ with small, firm breasts” (223). He also explains that to “examine the origins of aesthetic breast reduction, one must understand that [...] the reduction of the pendulous breast came to have meaning within another system of representation, that of race. [...] Smaller breasts represented ‘Germanness,’ as opposed to large, pendulous breasts, which were read as a sign of the primitive” (220).

47 *She wants to know why the surgeons removed half of her areolae without any pre-surgery discussion with her. They seemed to take it as a given that it would be OK with her, and/or that removing all but a small 1 ½ inch dark brown coin around her nipples is standard in breast reduction surgery. Why? Especially when doing so involves losing all those milk ducts that the aureolae represent? But then, since breast reduction surgery often results in the inability to nurse, those milk ducts are no longer important? And, because of her being of a “certain age,” those milk ducts would no longer have relevance? Finally, what role did perceptions of her race play in correlation with her being of a “certain age” in the decision to decrease her patrimony (why is there no equivalence with matrimony?) of milk ducts? Would stitching back a larger areola be more difficult than trimming the areola’s circumference, resulting in a lesser amount of stitching to be done?*

48 *Not only does she ask why half of her areolae were spirited away in surgery, but also how did she come to be born with such areolae? Were her areolae representative of an expanding universe? Even with the areolae trimmed back, controlled, restrained, that which generated the original diffusing areolae still obtains.*

49 Breast reduction techniques have evolved from the “anchor” scar to the “inverted T” to the “lollipop.” A plastic surgeon is quoted as referring to the “inverted T” as the “gold standard for the last 40 years.” From a nautical image on the chest to some kind of house construction tool image to a sweet to eat. Nice. How fitting. But none of the developments in breast reduction techniques pay any attention to the size of the areola, focusing almost entirely on reducing physical scarring at the center of the chest between the two breasts. This site of the largest accumulation of skin forms a junction.

50 *Junction at the center of her chest over her sternum, my armour against the world, the center of her anchor, that forms a material manifestation of the non-material but not*

immaterial pain at the core of her being, being in-between and thus nowhere centered, which IS HER center, evolving into the rage with which she is quick, a rage not yet aborted even though the larger than white-size areolae as stigmata of enduring pregnancy with fury have been cut short; clearly she must give birth to the rage to release it from her body, but not with writing words (and the irony is that she needed to seek relief from the pain of the loss in resorting to the words of the calm research writer, the reading and writing that held her in their embrace so early, so soon, against the injuries of those who should have simply loved her, lest she explode too violently and be unable to continue—to live) words which exist to control, repress, demarcate, label, strangle, while her body aches to blaze up from the page and scream in your face of skin being pulled from various directions, pulled from various directions, repeat after me, pulled from various directions has a tendency to become either “hypertrophic or keloid” (Gilman 220).

51 *In her search to have her breasts reduced to a manageable size, she came across a man, reputed to be the leading breast surgeon in the area, who told her that he would not do surgery on her as she would develop keloids. He then went to take a phone call, leaving her body chilled and naked from the waist up in his examining room, even though she defensively showed him her C-section scar, smooth and non-keloidal. Silently she dressed myself, left, tried to shake his spirit-killing oppression from her heart, entering out-of-body numbness again so as to function and not function.*

52 “Systems of domination materialize in the voices of women” (Spitzack 4).

53 On the other hand, the “lollipop” or “short-scar” technique involves no cutting and thus no remaining scar tissue at the center of the chest. Apparently this technique can also be described as a “vertical reduction mammoplasty with superior pedicle” or the “lollipop” technique (Otrompke 18). Reviewing the advantages and disadvantages of this new technique, reported in a news article published in 2005, the surgeon is reported to have been at work on the refinement of this technique for five years, after he became familiar with the techniques of two European surgeons who had been using the procedure on thousands of European patients for over 30 years.

54 *European patients bearing ghostly breasts “tip’t with vermilion” with tiny areolae. Treating this as an academic matter, she tells herself, is vital. It is a matter of survival.*

55 This is the technique portrayed in illustrations on the breast reduction section of the website of the American Society of Plastic Surgeons. One of the disadvantages is that “you cannot do it in a breast of more than a certain size, and in breasts in which you take off more than 800 grams from each side” (Otrompke 18). The above-mentioned website of the A.S.P.S.

says nothing about this caveat. In all the discussions about improvements in techniques, absolutely nothing is said about the areola.

61 Perhaps I disagree with Trinh Minh-ha when she writes “I say I write when I leave speech, when I lose my grip on it, and let it make its way on its own” (*Woman, Native, Other* 35). On the contrary, while I write I cling to an oral tradition precisely because it makes its way on its own, being less susceptible to control and a masculinist perception of order, as it sings, screams, moans, weeps, the words for which are but sickly pale labels for the reality of orality.

62 *But still she persists to bridge the gap between orality and writing in expressing her loss. I am her advocate pressing her case.*

63 The culture has yet to address the deeper hidden contexts of racial, gender, and sexual oppressions that manifest themselves in what the perfect breast should look like. Perhaps the Medieval standard for the breasts post reduction looking like two apples remains, but we are given no contemporary overt guidance as to what is a desired “shape,” the origin of the criteria, nor who decides. And silence remains about the areola.

64 She remains with the question whether, in having breast reduction surgery herself some six years ago, done by an Italian American surgeon and a dark-skinned Latino intern, both of them very attractive—sex is always in the frame—her multi-generational mixie breasts of a pale tan color with large brown areolae, lighter in shade than my darker brown nipples, and yet not as light a brown on the other side of the areola, a gradual change in terrain or text color, with no clear edge, were reconstructed to fit into white European-based criteria, and an unconscious emotional need for a racial edge between colors? Her personal reasons rested purely on historical distress at being female. Those reasons became corrupted by a system that racialized her original intent.

65 *Returning from the blurry haze to created time, she hears a voice calling her name. She opens her eyes. The woman in white, adjusting the IV by the gurney on which her body lies, says to her, “Everything went well.” Perhaps.*

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Judit Gadzi, Andrea Petö and Zsuzsanna Toronyi, (eds.): *Gender, Memory, and Judaism*

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1 Although research on Jewish women in Europe has grown quickly in the last two decades, both theoretical and geographical lacunae remain. Apart from the recent memoir collection *Hungarian Jewish Women Remember the Holocaust*¹, Hungary remains one of these geographic gaps in English-language scholarship. The road to such scholarship has proven a difficult one for several reasons. First because of an academic stumbling block: according to editor Andrea Peto, “gender studies are unknown in Hungary” (43). Second has been a reticence of non-Jewish feminists to engage seriously with committed Jewish women. Furthermore, since 1989 major religious institutions, both Jewish and Christian, have emerged from Hungary’s Communist years with traditionally minded rather than forward-looking attitudes toward women and gender roles. Despite these academic and political challenges, in 2006 a group of academics and activists organized a conference to consider the lives of Jewish women in historical perspective. The conference provided the genesis for the edited volume under review, entitled *Gender, Memory, and Judaism*, a text which both addresses and at times is subject to the aforementioned scholarly limitations.

2 “Diversities,” the title of the conference from which the articles were developed, also serves as the paradigmatic descriptor for the book itself. The editors divide the volume into three sections: “Traditions—Now,” “Gender and Religion,” and “Gendered Remembering,” although the subjects, methodologies, and tone suggest that most of these diverse essays could be placed in any one of these broadly-named sections. Across the sections, however, the essays are tied together by their use of history, historical remembering, or historically located interpretation of art to foreground Jewish women. Although the volume suggests the conference organizers chose the name “Diversities” because of Hungary’s location at the crossroads of East and West, the book embodies diversity in much more complex and thought-provoking ways.

3 Like Jewish feminism itself, *Gender, Memory, and Judaism* relies on a combination of images, stories, biographies, and art to do its work. The authors are academics and activists, old and young, secular and religiously observant, and from countries throughout the west. They rely on poetry, photographs, text, and oral histories to represent the lives of Jewish

¹ Rosen, Ilana. *Hungarian Jewish Women Remember the Holocaust: An Anthology of Life Histories*. Lanham, MD: University Press of America, 2004.

women and their experiences. Such an eclectic group of sources cannot present a unified picture, but herein lies the volume's greatest strength: it never allows the reader to create a simple, single-perspective image of Jewish women or feminism. Each essay challenges any stable or generalizing representation by considering the world from the position of a Jewish woman, historically or fictionally rendered.

4 The authors' contributions map a creatively diachronic world: one where history exists as both past and present. The history and memory of Jewish women from the past two centuries shape the lives of the contributors as well as their scholarship and art. Alice Shalvi's introduction to the collection epitomizes this connection between memory and the present. She humorously speculates on the reason for the invitation to introduce the conference and volume: "perhaps because I am among the oldest participants in terms of age, or perhaps because, as Andrea Peto assured me, I am a kind of living embodiment of the overall theme of continuity" (18). The volume suggests a stronger possibility: Shalvi is at once a historical actor and a contemporary force, her presence a kind of simultaneous past and present.

5 Shulamit Reinhartz's essay on biography and biographers recalls this theme. Her brief but poignant reflection "Finding My/Our History: The Case of Manya Wilbushewitz Shohat" demonstrates not only how her feminism has informed her scholarship, but also how her research has enriched her feminism. Reinhartz discusses how Shohat's work as an early kibbutz leader in Israel reinforced her commitment to "feminist distrust" in the reading of canonical histories. For Reinhartz, however, the captivating figure of Shohat could not be contained by the past: "I have her framed photo on my desk," she explains. Together Shalvi, Reinhartz, and many of the other contributors exemplify how history and memory play integral roles in modern feminist movements and scholarship.

6 Works such as Iris Parush's *Reading Jewish Women: Marginality and Modernization in Nineteenth-Century Eastern European Jewish Society*,² which suggests the sometimes paradoxical ways Jewish women's reading practices at once isolated and connected them with respect to European societies, and Paula Hyman's *Gender and Assimilation in Modern Judaism: Roles and Representation of Women*,³ which demonstrates how differences in geography meant significant differences in Jewish women's relationships with non-Jewish society, capture the wide variety of sometimes contradictory ways in which Jewish women have encountered modernity. Thus a volume such as *Gender, Memory, and Judaism* that

²Parush, Iris. *Reading Jewish Women: Marginality and Modernization in Nineteenth-Century Eastern European Jewish Society*. Hanover, NH: Brandeis University Press, published by University Press of New England, 2004.

³Hyman, Paula. *Gender and Assimilation in Modern Judaism: Roles and Representation of Women*. Seattle: University of Washington Press, 1995.

preserves or creates tensions among its essays mirrors its complex and often conflicted subject. But this volume's unevenness—in terms of article length, tone, clarity of translation, and academic contribution—also becomes its most significant liability. The essays vary widely with respect to the amount of original research and the strength of their interpretations of that research. While many of the authors provide close reading and insightful analysis, others simply recount historical or biographical events without discussion of their meaning in context or importance for other scholarship. The articles also assume widely varying degrees of familiarity with Judaism, gender theory, and Hungarian history. For this reason, although the volume offers some excellent confrontations with issues of Jewish women and history, nonspecialists may have difficulty understanding the relationships among these issues.

7 Another concern lies in the volume's conflation of the concept "gender" with the concept "women." Although this does not detract from the information contained in the volume itself, the repetition of the equation "gender = women" can be used to perpetuate the stereotype that only women have gender or that only women should concern themselves with understanding how sexual difference is constructed. Although the authors and editors of the volume certainly do not espouse such a view, the work could nevertheless suggest to a reader without a background in gender studies that gender is an academic topic—or that feminism is a movement—that is solely for and about women.

8 Despite the liabilities of the volume's uncompromising commitment to diversity and its theoretical language, the editors have created a highly provocative and challenging work. Its diverse authorship and media offer a model for all scholarship that seeks an element of activism.

List of Contributors

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