

Autopathography and Audre Lorde's *the Cancer Journals* as a Narrative of Illness: Revising the Script of Disease

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ABSTRACT

Audre Lorde's autobiographical text *The Cancer Journals* (1980) functions as an autobiographical manifesto by reformulating the dominant discourses about the treatment of breast cancer in the Western society from the point of view of the patient. Lorde makes carefully wrought arguments against the use of prostheses and reconstructive surgery as treatments for breast cancer. She uses autopathography not just as a therapeutic form of writing, but also as a political act. For Lorde, her black, feminist politics are inseparable from her identity and for these reasons they emerge in her autobiographical writing.

By placing Lorde's text *The Cancer Journals* in the context of other autobiographical narratives of illness such as Susan Sontag's *AIDS and Its Metaphors* (1989), Nancy Mairs' *Plaintext: Essays* (1992), Cornelius Ryan's *The Private Battle* (1979), Anatole Broyard's *Intoxicated By My Illness* (1992), and Robert Murphy's *The Body Silent* (1987) this study considers some of the structural and ideological issues which characterize this form of writing. This paper also seeks to contextualize the autobiographical argument in terms of what G. Thomas Couser has defined as autopathography. Given the premise that autopathography is an author's construction of the self—it is also useful to consider the ways in which illness disrupts the construction of identity by changing the course or length of a life and by literally disfiguring or disabling a body. A person's resulting changed perspective on life and the body manifests itself in autopathographic writing as a revelation about the status of the body as well as—as a call to action against the societal marginalization of the ill. Autopathographies have some very practical goals. They disseminate information about the author's disease, try to correct misconceptions and the dehumanization of patients as well as to provide insight into suffering and to the meaning of illness.

Keywords: Autobiographical narrative of illness (autopathography), *The Cancer Journals*, reconstructing identity, trauma, cosmetic mastectomy.

1. INTRODUCTION

Patient authored narratives of illness play a challenging and revisionary role in the evolving literature of disease. Because illness narratives combine the work of autobiography with writing about disease, they have a means of revising the scripts of those who are ill. They offer a corrective for the scientific depictions of the disease by admitting the patient's life story into the

portrait of the illness. G. Thomas Couser has characterized "autobiographical narrative of illness or disability" quite usefully as "autopathography" (65). He suggests further that autopathography is a "sign of cultural health—an acknowledgment and exploitation of our condition as embodied selves" (Couser 65). Audre Lorde's book *The Cancer Journals* (1980) is not only a useful example of this genre, it also contains within it a greater project, an explicit manifesto for women with breast cancer. Lorde's autobiography takes as its task a revision of the model of the breast-cancer patient in an attempt to provide patients with alternative roles to play during their illness. Within *The Cancer Journals*, Lorde

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disrupts contemporary stereotypes of disease and "appropriate" social treatment of breast cancer by using autobiography, the text which constructs the self, as a locus for performing the body's illness. She places her disease in a humanizing context, the life story. Her life writings are reinscribed by the presence of the disease, and because she is dealing with a potentially life threatening cancer, the text is both energized and haunted by the ghostly visage of death.

Lorde's autopathography is an attempt to redress the balance of power among women, their bodies and the social constructions of illness. In other words, she seeks social power for women with breast cancer by affirming and legitimizing their social and human rights as patients. M. Foucault (1977), P. Bourdieu (1987) and Van Dijk (1989) all interpret social power as discursive control: who has access to the various types of discourse, who can and cannot talk to whom, in which situations, and about what. Lorde's discourse addresses all types of the American society; and it has ideological, political and historical implications. The author is speaking with power because she represents many females whose medical and social situation is similar to hers. Ruth Wodak explains in *Discourse of Discourse* (1996), that "Discourse does ideological work: Ideologies are particular ways of representing and constructing society which reproduce unequal relations of power, relations of domination and exploitation" (18). Lorde dictates the social oppression, and racial discrimination black females with breast-cancer experience in the white hegemonic society. Lorde's discourse has a purpose and intention: she defends the rights of this dynamic group of women, humanizes their illness, and fights for their individuality.¹ Taking this context into consideration, Lorde's text implies a social action. It gains momentum from Lorde's history of activism and reclamation of her status as a black, feminist poet. In "A Manifesto for Cyborgs: Science, Technology and Social Feminism in the 1980's" Donna Haraway describes women's identities as fractured and borrows from Chela Sandoval's argument that women of color have defined themselves "by a conscious appropriation of negation" (qtd. In Haraway, 197). The concept of reclaiming the "othered" or negated self is crucial to an understanding of Lorde's argument. She has chosen to oppose the ideology of disease. Her radical re-writing of the treatment of cancer in Western society suggests that the previous definitions of a woman's body are completely at odds with a patient's well-being. She

seeks the freedom to recover from her illness in any form she can, deliberately blurring the boundaries of "normal" appearance to escape the tyranny of the "perfect" body. Haraway describes how modern biology has become a "problem in coding" one of the examples she cites as the "medical constructions of our bodies" (206-7). Autopathography is a means for Lorde to reconstruct the missing human elements of the body which medicine and technology lose sight of.

Couser suggests that autopathography is characterized predominantly by female-authored texts. He writes that because illness and the body are more closely associated with the female body, and that Western thought has privileged the mind over the body, illness and the body have been repressed in life writing (Couser 65-8). This theory, Anne-Hunsaker Hawkins contends, may reflect the literature written prior to 1900, but it ignores a large number of male-authored texts particularly since the genre really began evolving in the latter half of this century (Hunsaker 3). It may be more pertinent to look at the simple fact that prior to 1950 antimicrobial agents were not widely available and proportionately, vastly fewer patients survived to write about their disease.² Given the statistical change in survival, patients in the latter half of this century do not only live longer-but in non-curative cases like some cancers, patients live longer with their disease.

Couser also suggests that women can engage more freely in autopathography because they have always been more "defined-and thus confined-by their anatomy and can thereby be freer to write about their bodies and their disease (67). Couser's theory is both useful and provocative because of its plausibility in light of much recent feminist criticism which addresses the marginalized status of the female body, and the ways in which illness may result in a feminization of the body, characterized by increased vulnerability and a loss of bodily strength. However, his definition of autopathography as a women's genre seems a bit misleading, because there are numerous examples of male-authored autopathographical writings, at least in the twentieth-century such as Cornelius Ryan's *The Private Battle* (1979), Anatole Broyard's *Intoxicated By My Illness* (1992), Robert Murphy's *The Body Silent* (1987) to name but a few. All of these books are compelling to read and bear some structural and ideological similarities to Lorde's text, which will be addressed later in this paper. However, what Couser may be identifying is that

there are more autopathographies of women that construct the narrative of illness in some specific ways that may reflect a somewhat gendered treatment of sick people in Western society. Furthermore, the way men and women are actors of their autobiographies and exempla of their disease and the way their performance is greeted by the family and friends may be gender-inflected as well.

2. THE CANCER JOURNALS AS AUTOBIOGRAPHICAL MANIFESTO

The Cancer Journals is a revealing example of autopathography. It is not like nineteenth-century autobiographical narratives which are characterized by their dramatic force, simplification and objective straightforward medical writing. Such medical writings are also chronological in nature and sometimes the dramatic narrative which gives life to the patient's story is removed in the interest of science. Furthermore, the rhetoric of suspense in these medical narratives makes them read like Sherlock Holmes mysteries. These medical stories are also educational; they can be used for teaching medical communication skills.³ In *Doctor's Stories: The Narrative Structure of Medical Knowledge* (1991), K. Hunter explains, these medical narratives share an interest in fostering education and understanding and are explicit in nature and directly concerned with medicine (33-45). Audre Lorde's text is different in the sense that it is an attempt for reconstructing a female patient's life. Unlike medical case histories/stories which narrate the course of disease, and unlike much autobiography which often spans many years of the autobiographer's life, Lorde's autopathography is limited in scope. It addresses approximately one year of her life, the year she was diagnosed with and treated for breast cancer. However true to "pathography," a term which Oliver Sacks (1990) coined to refer to biographies that combine science and art, Lorde's text uses a literary space to narrate her illness.⁴ But *The Cancer Journals* criticizes also social conceptions, stereotypes, and images about breast-cancer patients in the dominant white American culture. Furthermore, Lorde's autopathography reflects her lifework, the poetry, and activism that characterize her self.

Lorde inscribes her text not just with her body and her cancer but with a call to action that is representative of her lifelong revisionist politics. Couser suggests that it is

precisely Lorde's feminism that "enabled her to respond to breast cancer in an unorthodox way" (68). But what is striking about her autobiographical act is that she is not only finding a means for dealing with the disease, but that she transforms the private space of journal writing into a public space when she reads her journals as a series of lectures and then later shapes them into a book. The journals are not merely reflections on her illness or revelations about the renewed value of health, they are also constructed of a carefully reasoned argument against the Western cultural constructions of breast cancer. She argues compellingly against the use of breast implants in post-mastectomy cancer patients nearly a decade before the class action suit against Dow-Corning for the side effects associated with silicone breast implants. Lorde uses her own testimony convincingly as support for her claim.

As she memorializes her disease, Lorde reconfigures the role of cancer patients in society by identifying some of the ways constructed and followed in dealing with the disease. She writes:

When other one-breasted women hide behind the mask of prosthesis or the dangerous fantasy of reconstruction, I find little support in the broader female environment for my rejection of what feels like a cosmetic sham. But I believe that socially sanctioned prosthesis is merely another way of keeping women with breast cancer silent and separate from each other.

(*The Cancer Journals* 116)

Her words indicate the utter lack of a community formed by cancer patients perpetuated by their invisibility to each other. Instead, Lorde proposes a provocative alternative to silent suffering when she writes: "For instance, what would happen if an army of one-breasted women descended upon Congress and demanded that the use of carcinogenic fat-stored hormones in beef-feed be outlawed" (*The Cancer Journals* 116). Breast cancer becomes an inanimate actor in the drama of Lorde's feminism. She exposes the ways in which a mastectomy grossly disrupts the balance of her bodily and psychic existence. The potential virulence of her disease forces her to choose a mastectomy as a treatment necessary for survival. But because mastectomy involves not only the painful excision of cancer cells, but often also involves the removal of the breast, an organ which defines social constructions of the female body and female beauty, this particular operation is riddled with an inordinate amount

of emotional baggage.

Unlike most other operations that require organ removal, mastectomies are self-evident if a woman does not wear a prosthesis or have reconstructive surgery. She is literally disfigured because the contours of her bodily geography have been altered. Lorde's comments problematize the use of prosthetic breasts not because of the physical side effects that have since been exposed, but because of the psychic damage that is glossed over by the illusion of having reconstructed breasts. By reconstructing their original figures, the women can not only return undetected to the ranks of the healthy and to a place before the trauma of cancer, but they can also deny to themselves their battle with disease and pretend that their bodies are whole, unflawed.

Lorde's argument points to the lack of a sanctioned social space for women without perfectly formed bodies. She is exposing the value judgments implicit in desire for such bodies after surgery by patients in Western society. She underlines the troubling fact that such cosmetic demands are placed on bodies that have just fought valiantly in the battle for their lives and survived - and then are told to hide their wounds. These women are awarded no honor and no red badge of courage for battling cancer. Instead, their mastectomy scar is treated with shame. The presumption that Lorde is fighting against is the idea that women should pretend to themselves and to each other that the cancer never happened; that a diseased person should bear no marks of their mortality. Instead, the body exists primarily as an ornament of their gender. Lorde's journals force the reader to reconsider the value placed on the body, on "normalcy," on healthy, and on "femininity" and to review at what cost to psychic health such value judgments are made. Her text unmask the bodily charade of prosthesis and dramatizes the way the ill not only have to do battle with disease, but also with society's ideals of embodiment.

Another aspect of this performance is the interaction of Lorde with the medical community. In his essay "Performing Persons: A Locus of Connection for Medicine and Literature," William Monroe suggests that the patient functions as a physician's text and recognizes the significance of a patient's performance during illness (26). The idea of a patient as a text is underscored when the patient "performs the self" in the genre of autobiography (27). He observes that "in the medical arena, where the making and maintaining of persons is

overtly threatened by trauma or disease, exercising powers and receiving acknowledgment of performances is quite literally of vital importance" (29). In other words, the way patients are received by their medical and familial audience during their illness can affect the course of their disease. He suggests that some performances "rather than bonding to the world, succeed insofar as they release the performer from ethical responsibilities and relationships of trust" (29-30). This aspect of role-playing is not specific to the patient, it also refers to health care professionals and family and friends of the patient. There are those who would argue that a masking of the body is necessary to some patient's emotional well-being, and Lorde does not dispute this position. She merely seeks the possibility for more than one kind of treatment of the disease. Monroe complicates this idea by suggesting that one reason a patient "resists the pressure to perform as an instance of a condition, disease, or syndrome" is that this kind of performance prevents the "physician from retreating into a purely scientific role" and from looking at the illness as a part of a "complex psychosocial situation" (Monroe 34-5). Certainly, Lorde is asserting her individuality on her community by resisting the prosthesis. She does not allow her doctors and nurses or her society the easy escape of prosthesis. They, too, must contend with her as a person with cancer and see the mark of her loss in the absence of her breast.

Lorde recounts the surreal experience of receiving a prosthesis from a "Reach For Recovery" volunteer as a means for exposing her indictment of this action. She writes:

I came around the bed and stood in front of the mirror in my room, and stuffed the thing into the wrinkle folds of the right side of my bra where my right breast should have been. It perched on my chest askew, awkwardly inert and lifeless, and having nothing to do with me I could possibly conceive of. Besides it was the wrong color, and looked grotesquely pale through the cloth of my bra. Somewhere up to that moment, I had thought, well perhaps they know something I don't know and maybe they're right, if I put it on maybe I'll feel entirely different. I didn't. I pulled the thing out of my bra, and my thin pajama top settled back against the flattened surface on the right side of the front of me . . . I looked strange and uneven and particular to myself, and therefore so much

more myself and therefore so much more acceptable than looked with that thing stuck inside my clothes. For not even the most skillful prosthesis in the world could undo the reality, or feel the way my breast had felt, and either I would love my body one-breasted now or remain forever alien to myself.

(*The Cancer Journals* 44)

Lorde's discussion of the prosthesis underscores her need for an authentic self. Her means for coming to terms with her disease cannot be by reconstructing her absent breast for herself or for the public. She finds recovery in facing the flattened contours of her ailing body. In her case, the cosmetic sham of the prosthesis is highlighted by its inappropriate and inconsiderate whiteness, making it twice-removed from the body of a black post-mastectomy female.

Thus Lorde's autopathographical project manifests some of the issues that are hidden behind the social mask of prosthesis. Sidonie Smith's discussion of autobiographical manifestoes as texts that use specific strategies that lead an "outlaw to a kind of political empowerment" illuminates Lorde's activity in *The Cancer Journals* (155). Smith suggests that the use of self-fragmentation "to reveal the cultural constructedness of any coherent, universal subject," is an effective tool for the oppressed (155). Certainly, Lorde's discussion of the fragmented, post-mastectomy body plays a role in the emancipatory politics of breast-cancer patients. Her goal is to bring to light the way breast-cancer patients are made to feel about their disease; that they must reconstruct their bodies or become completely marginalized by society. With the loss of a breast, a woman feels not only physical pain and loss, she is also made to feel that she has lost some crucial aspect of her sexuality, femininity, and beauty.

Lorde's willingness to perform a new, socially unsanctioned role in public greatly strengthens her argument. She is fighting for the legitimization of wearing her disease, of being a post-mastectomy female without a prosthesis, shame or social stigma. She is replacing the falseness of prosthesis with the reality experienced not only by the suffering of her physical body; but also with the suffering experienced by her psyche—ravaged by the well-meaning but imposing forces of society as manifested by the "reach for recovery" volunteer. The imposition of the "appropriate" way to deal with the

psychological readjustment to mastectomy is further exemplified by the comments made by a nurse in the doctor's office at Lorde's post-operative visit. Upon seeing that Lorde was not wearing a prosthesis, the nurse said, "You will feel so much better with it on. And besides, we really like you to wear something at least when you come in. Otherwise it's bad for the morale of the office" (*The Cancer Journals* 59). What this statement underscores is one of the underpinnings of socially sanctioned breast prosthesis. Post-mastectomy women are expected to wear prosthesis not predominantly because they will make them feel better, but because healthy people and potentially sick people do not want to be told or reminded of the pound of flesh that these women have to pay for their survival. Lorde raises the very real question of whether women fighting for their lives should have to create the illusion of health to reassure the healthy and the people who might have to face the same struggle. On the contrary, her vitality and her survival (as manifested by her presence in the doctor's office) should be perceived as a morale booster, as a sign that there is a life after cancer; a life that is the patient's to live, define for herself, perform even single-breasted.

3. INTERTEXTUALITY AND HUMANIZING ILLNESS IN THE CANCER JOURNALS

Julia Kristiva (1980), a French Semiotician who was influenced by the work of Bakhtin, believes that "any text is constructed of a mosaic of quotations; any text is the absorption and transformation of another" (66). Bakhtin and Kristiva, G. Allen in *Intertextuality* (2000) states, "share [d] an insistence that texts cannot be separated from the larger cultural or social textuality out of which they are constructed" (36). C. Keep, T. McLaughlin and R. Palmer (2002), on the other hand, assert that, a literary work "is not simply the product of a single author, but of its relationship to other texts" (Keep et al. 1). Moreover, N. Fairclough in "Intertextuality in Critical Discourse" (1992) states that texts "are inherently intertextual, constituted by elements of other texts" (270). It is useful, therefore, to consider Lorde's text in the context of other autopathographical narratives written in the second half of this century. Anne-Hunsaker Hawkins suggests in her book *Reconstructing Illness: Studies in Pathography* (1993) that pathographies fall into three groups—testimonial pathographies, angry pathographies, and pathographies advocating alternative modes of

treatment (4). In so doing, she underlines some of the motivations to write autopathographies, that is, to narrate an illness, to rail against the fates, to advocate for better or different medical treatment of a disease. But this method seems overly simplistic because Lorde's text as well as several other texts which will be referred to in this section are not contained within the borders of any of these models. In fact, these are merely characteristics of autopathographies. It might be more useful to point out that most narratives of illness are limited in time from the time of diagnosis and during the duration of treatment, which could be until death and it might also be useful to say that most narratives of illness make arguments against the isolation and the lack of dignity associated with disease. Many autopathographies are in some sense a manifesto for the reconceptualization of illness, while at the same time the motivation to write is described as a therapeutic reconstruction of the identity fragmented by the gap between the diseased body and the healthy mind.

One of the reasons to consider the process of writing autopathography as a conglomeration of the activities that Hawkins suggests is that there seem to be experiential links between the emotional stages of illness and the shape that the narratives take. Janice Morse and Joy Johnson in *The Illness Experience: Dimensions of Suffering* (1991) have developed an "illness—constellation model" which summarizes the stages a patient passes through during the course of a serious illness. There are four main stages of the illness constellation model: the first stage is the "stage of uncertainty" characterized by suspicions of illness, careful reading of the body, and feeling overwhelmed. The second stage of illness is the "stage of disruption" which occurs at the time of diagnosis when patients must relinquish control and sometimes distance themselves from the illness in order to make decisions. The third stage is "striving to regain the self" when the patient tries to make sense of the disease, preserves oneself, renegotiates roles, seeks goals, and seeks reassurance. The fourth stage is "regaining wellness" characterized by taking charge, and seeking closure (Morse and Johnson 321). It seems likely that although much journal writing takes place throughout the stages of illness, it is in the final two stages that the argumentative autopathography is written.

For purposes of illustration, it is useful to point out that Cornelius Ryan's book *The Private Battle* (1979) holds most closely to the schema described above. The

first stage of his autopathography is a reproduction of his pathology report which gives the diagnosis for his disease, prostate cancer. He spends the early part of his narrative describing in detail all the bodily symptoms that lead to his discovery of the disease and the later portions of his book illustrating the way he came to terms with his disease, disability and finally with his mortality. Throughout the text he exposes the lack of adequate information, care, and social concern for cancer patients. The following section of the paper will look at the way the pathographies of Murphy, Ryan, Mairs, Broyard, and Sontag are ideologically and structurally related to the text written by Lorde.

The idea that the ill are supposed to compensate for the feelings or delicacy of the healthy is not at all specific to breast-cancer survivors. It is particular to any person whose body is visibly marked by their disease or disability. Robert Murphy's autopathography *The Body Silent* (1987) is an example of how ill treatment of the diseased and disabled crosses gender lines impartially. Murphy's book describes how he became a paraplegic because of a tumor in his spinal column and how this paralysis radically changed his position as a healthy, white, male academic to a barely visible being. He observes that in his experience "the social relations between disabled and able-bodied are tense, awkward and problematic" (*The Body Silent* 86). His narrative exemplifies how bodily impairment isolates the diseased from the healthy. Murphy, like Lorde, describes how the diseased are othered, marginalized. When he became bound to a wheelchair he literally dropped out of conversations because they mostly took place about a foot over his head. Murphy contends that nobody asks about disability because "this would violate all the rules of middle class etiquette" (*The Body Silent* 87). He describes how even physicians only want to know about the hard facts of the disease. The difficulty with this attitude is that it "ignore[s] the broad range of ideation and emotion that always accompanies disability" (*The Body Silent* 87-8). So, he, like Lorde, is forced to perform his illness textually to get the attention of an audience which is always looking away.

However, Murphy also suggests that with estrangement "has come a greater urge to penetrate the veneer of cultural differences and reach an understanding of the underlying unity of all human experience" (*The Body Silent* 102). In short, he feels that his marginalization as a paraplegic has given him the insight

of an impartial observer, always outside the mainstream events. Thus, he feels he is in a place to observe how the personhood of the disabled is completely hidden behind the mask of bodily disease. All that people see is paraplegic, not professor, not man.

Like Lorde, Murphy fights for the possibility for more dignity for the diseased and disabled. He cites the youth culture in American society as the culprit for society's problematic treatment of the sick. It is the bodily difference, he argues, the perceived departure from a human standard that separates the healthy from the sick. And because of this departure from bodily wellness society ostracizes the diseased from normal community, treats them with a misplaced politeness and thereby erases the person behind the mask of illness. Murphy is reconstructing an identity for the sick from the shattered pieces that make up a diseased identity.

Murphy also addresses some of the gender identity issues faced by the ill and disabled. He describes the literal and figurative emasculation of paralysis. Lorde pointed to the way women are perceived as less feminine after mastectomy. Murphy points out that the weakening and atrophy of the body "threaten all the cultural values of masculine strength, activeness, speed, virility, stamina, fortitude" (*The Body Silent* 94-5). The juxtaposition of these two texts can be instructive because it indicates some of the ways pathology is socially inscribed for both men and women. It also points out the different physical characteristics that are still at issue for men and women in societal eyes. Clearly, the persisting model of femininity is defined by appearance while the masculine model consists of the ability to be strong and to take action.

Murphy argues that his readers consider the site of disability as another kind of marginalization. Similarly *The Cancer Journals* is not only a pragmatic exhortation against the treatment of the ill by society. In addition, it suggests an alternative means for perceiving the changed contours of post-mastectomy bodies. Lorde takes the suggestion of such a reconception a step further by proposing a new paradigm for the body when she alludes to her own body's resemblance to the mythic Amazon warriors of Dahomey, who have their right breasts cut off to make them more effective archers (*The Cancer Journals* 34-5). She reinscribes her body's geography not as victimized and dying, but as a strong warrior who must change her body for pragmatic reasons, to win the war. Her use of mythology provides a constructive way of revising the diseased body as mythical, powerful, and

feminine—rising above the fear, dismay, shame or despair more often associated with this illness. Notably, Lorde's use of mythology provides a normative context for single-breasted women.

The act of reconceiving the body is vital to the emotional health of the patient. Susan Sontag (1989) addresses the pejorative effects of metaphor in the battle against disease, when she notes that:

The wars against disease are not just calls for more zeal, and more money to be spent on research. The metaphor implements the way particularly dreaded diseases are envisaged as alien "other," as enemies are in the modern war; and the move from the demonization of the illness to the attribution of fault to the patient is an inevitable one, no matter if the patients are thought of as victims, by the inexorable logic that governs all relational terms, suggests guilt. (*AIDS and Its Metaphors* 11)

Sontag's work calls specifically for a revision of the metaphors of disease. She sees the need to literally change the words used to describe illness and patients so that they can have less embattled place in the American society. This reinscription of illness begins with the writing of autobiography. But Sontag's contention is that this revision needs to happen on a societal level as well. Sontag suggests that language has the power to exile and that the alienation of metaphors for the diseased contributes to their sickness. Because of the terms that have been chosen to define illness, sometimes patients are perceived to be at fault for their disease.

The move to re-write metaphors for illness is not to say that autobiographies seek to euphemize illness. Clearly, one of the goals for Lorde and Murphy was to present in a coherent language an authentic self and that included a truthful representation of their illness. For example, Lorde seeks to unmask the "fantasy of reconstruction" recognizing that the physical and verbal illusion of recreation suggests a complete recovery and return to the pre-traumatic state. Nancy Mairs's self-conscious description of herself as a "cripple" (9) in her autopathographic text *Plaintext: Essays* (1992) is in fact a dismissal of euphemism. She describes how she shuns the politically correct "handicapped" precisely because it is imprecise and unreflective of what she perceives her condition to be—as a woman whose motor abilities are

debilitated by multiple sclerosis (*Plaintext: Essays* 9). Mairs writes how she deliberately chose the word cripple partially because:

People-crippled or not-wince at the word 'cripple,' as they do not at 'handicapped' or 'disabled.' Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates/gods/viruses have not been kind, but who can face the brutal truth of her existence squarely. As a cripple, I swagger. (*Plaintext: Essays* 9)

This narrative suggests that Maris like Lorde and Murphy wants society to face who she is and that part of her identity that most dismays it—the body that fails hers. In a coherent meaningful narrative, she debunks the language that masks the reality of her suffering. And by doing so, she makes no apologies for her illness. In fact, she approaches it with a sense of humor and the desire to shape her illness into a means of attaining a personal style, the signature of the fortitude she has gained in the face of bodily obstacles.

The desire to integrate the disease into their identities and simultaneously to people the history of their disease emerges as a characteristic of autopathography. Anatole Broyard (1992) converts his illness into a narrative and describes how language and personality can rewrite a person's perception of disease. He indicates that he thinks that:

Only by insisting on your style can you keep from falling out of love with yourself as the illness attempts to diminish and disfigure you. Sometimes your vanity is the only thing that's keeping you alive, and your style is the instrument of your vanity. It may not be dying we fear so much, but the diminished self. (*Intoxicated by My Illness* 25)

Broyard, a literary critic by profession, spends a good portion of his very witty autopathography theorizing about narratives of illness. He draws illness as a character in his narrative whom he must face, the combatant in the battle for survival. But Broyard, like the others, recants the prescription of patient as a helpless victim. He refuses that role. He wants the opportunity to fight against disease because he finds that the advent of illness filled him with "desire-to live, to write, to do everything" (*Intoxicated by My Illness* 4). Like Lorde, Broyard imposes his personality on his disease; he will not sit

back and be another casualty of disease. By refusing his performance as a patient, there is a possibility of life with cancer, a chance to regain some of the human dignity which he accuses illness of having robbed him.

Similarly, although with less *joie de vivre* Ryan in *The Private Battle* (1979) describes how the medical profession contributes to the loss of self. Like Lorde's post-operative visit, Ryan describes his routine work-ups with dismay: "It's dehumanizing, you take off your clothes and you are in their hands, defenseless, unable to decide when you can come and go . . . you're a patient—without dignity or a sense of self" (*The Private Battle* 153). Stanley Reiser (1992) argues that it is in part the fault of modern technologies that there is such inhuman treatment of patients by health-care professionals. Prior to the twentieth-century a patient's story was the primary means of examining and diagnosing disease. But during the twentieth-century, the technologies increased so that machines and tests offer the diagnosis of choice. Reiser points out that the price for this advance has been that "portraits of illness drawn with numerical and graphic evidence omitted features that came from the subjective life of the patient" (46-7). This omission also precludes much human contact with the patient at all, removing the semblance of human involvement and the reassurance of a bedside manner along with it.

The autopathographical gesture is to remind society and caregivers that the strategic quality of modern therapies has residual effects on the patient. It is often remarked as well that health care-professionals are callused because they face disease and dying everyday, but this does not change the fact that most patients face serious illness only once. Illness narratives are the writing of this crisis in treatment. The other aspect of autopathography that gets expressed repeatedly is the necessity to write about the trauma. Lorde describes a need to break the silence (20). Lorde states explicitly that she believes that:

What is most important to [her] must be spoken, made verbal and shared, even at the risk of having it bruised and misunderstood. That the speaking profits me, beyond any other effect. I am standing here as a black ... poet and the meaning of all that waits upon the fact that I am still alive, and might not have been Death on the other hand is the final silence. (*The Cancer Journals* 19-20)

Lorde's words in the previous quotation make it clear that she writes most of all for herself, for survival, for a chance to come to terms with her own life as a means towards recovery. Her descriptions are informative, coherent and makes vivid the material and figurative constructedness of her recovered body.⁵ Like the meaningful coherent narrative of Ryan, Broyard, Murphy, and Sontag, Lorde's argument is not independent of context and situation. Although her disease disrupts the narrative of a healthy life and exposes her body to fear and trauma, it does not completely stifle the narrative. The disease changes the facts of the tale, re-values the status of the body in the hierarchy of living. But the thread of writing continues at least in a coherent essay form.⁶

Ryan describes a similar difficulty in working on his last historical text. It is only when it becomes clear that his cancer is terminal that Ryan begins writing his final book and he is very concerned that the disease will taint his historical writing. He writes: "Lately we have been doing some of our best work on the book at night. I am very excited about it, and in spite of the appalling creature I have become, I am careful to let nothing of myself show through the work. If I did Katie would spot it and edit it out" (*The Private Battle* 347). It is understandable that he would not want his academic writing to suffer. But his need to perform his health to his historical audience may have cost him emotional and physiological well-being. His reference to himself as "the appalling creature I have become" also points to an apparent self-loathing. His fear is that his bodily ailments will be translated into his intellectual process and appear symptomatically in his writing. This fear is present in his decision to keep his illness a secret as a means of protecting his authorial credibility. After completing that last book, Ryan describes how "I don't think I ever realized what a strain it was keeping cancer a secret from publishers and far-flung friends" (*The Private Battle* 389). One of the key differences between Ryan's text and Lorde's emerges as his need to conform to the masculine stereotype of strength, health and vigor despite its pejorative effects on his health as opposed to Lorde's need to counter the feminine stereotype. Ryan feels that he has to compete with the healthy or cease to be human. His words point to the need for a functional place for the ill in the American society that is not the locus of pity and self-hatred. They also point to the fact that feminism has given Lorde a tool with which to fight stereotypes, a tool which Ryan has no access to.

The Cancer Journals is about creating an alternative

space for post-mastectomy females. Lorde wants the individual patient to have more than the dichotomy between acceptable as healthy and productive and unacceptable as diseased and outcast to choose from. She opts to remain politically active; to use the "transformation of silence into language and action," because even with cancer she is a fighter (*The Cancer Journals* 20). She continues her reclamation of differences on the embattled grounds of illness using the skills she had honed all her life as a black, feminist poet. Lorde realizes that one of the difficulties of the patient role is that it is usually not scripted by the diseased. The patients have to hand over control to the medical community when they are diagnosed. They seek a cure not by a simple will to survive but via invasive surgery, chemotherapy, and radiation treatments all chosen by the bevy of specialists who treat disease. What that medical experience rarely provides is a therapy for the frustration and the isolation imposed by illness. Lorde sought the support of her own community. She describes how she "wanted to talk... [and] sit down and start from a common language, no matter how diverse" (*The Cancer Journals* 49). Her friends help her to meet and discuss breast cancer with others who have suffered from the disease. The networking that makes this possible for Lorde is obviously one of the things that helped her come to terms with her disease. But what it does not reflect is that 60-80% of the middle-aged women who have breast cancer die in less than five years. So, in truth some of the links in a patient network are permanently unavailable. Others may have no desire to discuss their cancer, and some patients survive emotionally by denying the severity of their condition.

However, to be fair, many patients do share this need for community. Ryan describes how he experienced a special kinship among cancer patients. He writes how the "desperate perceptions of [their] lives, so hard for [them] to bear, can never be truly understood by those who don't have cancer. Not even by the specialists who work to save us" (*The Private Battle* 177-8). What Ryan and Lorde are pointing to is the inability of the healthy to comprehend the potential death sentence of cancer and how the narrative of illness can only hint, during the brief moments of reading, at the enormity of living with a fatal disease. His words points to the limitations of autopathography, its inability to express the emotional burden of traumatic events. Autopathography cannot stand in for real experience, but this can be said about almost any narrative. And autopathography can expose

somewhat the gap in experience between the sick and the healthy. For example, Lorde's description of feelings of isolation was exaggerated when healthy people treated her differently when she became ill. She writes how

There were people who avoided me out of their own pain or fear, and others who seemed to expect me to become someone other than who I had always been, myself, rather than saint or Buddha. Pain does not mellow you, nor does it ennoble, in my experience. It was hard not to feel pariah, or sometimes too vulnerable to exist. (*The Cancer Journals* 55)

Such a disheartening description of a change in treatment by friends or colleagues seems to be fairly characteristic of autopathography. Broyard, Sontag, and Murphy all report similar experiences. Part of the desire to write autopathographical narratives may stem from a desire to break through the social veneer of fear and politeness that shapes the social interactions between the sick and the healthy. Broyard indicates that this veneer is present with doctors as well as with people who have little contact with disease. He wishes that the "doctor would scan" him as well as his disease, that he would "grope for [his] spirit as well as [his] prostate. Without some such recognition [he is] nothing but [his] illness" (*Intoxicated By My Illness* 45).

Broyard is urging doctors to see the humanity behind the façade of illness; to be treated as more than a diseased piece of protoplasm in need of a cure; to be returned to the landscape of the living by being granted the dignity afforded to the human (*Intoxicated By My Illness* 33-42). The writing of autopathography offers the sick person a means of seeking a sympathetic audience for their "real" identity. Narrating illness becomes a way of constructing and shaping an identity that has been transformed by illness. The written text is a place where the patient can authorize the self to be the mind and soul (not just the failing body) in front of an immortal audience. This way the author can survive to tell the story of a life short-changed by disease. It is a mind's way of tricking the final silence of death. The genre of autopathography then is a crusade to rewrite earlier conceptions of disease by freeing the sick from the containment of a language paralyzed by inflexible paradigms and outdated scripts.

5. CONCLUSION

In re-writing the script of the disease, Lorde creates the world she envisions; that is, she creates a new discourse enabling her to invent a world in which truths about her disease, identity, and subject hood can be materialized. Lorde's disease in her autobiography does not affect her narrative prose which re-inscribes, at least at the level of syntax and diction, hegemonic ways of representing and reconstructing her identity. However, as this paper has explained, the "traumatic" textual features of Lorde's poetry fail to create fully cohesive "healing" narratives, especially that Lorde's own traumatic experiences of racial distinctions affect her poetic writings which work to produce perhaps not fully assimilable but nevertheless present representations of subjective relations to the world that would otherwise be unrepresentable.

The Cancer Journals combines the work of autobiography with writing about illness, an autopathography that disrupts contemporary stereotypes of breast-cancer patients and creates alternative roles for such patients to play in society. As a black feminist writer, Lorde disregards and escapes the tyranny of masking the body through the cosmetic sham of prosthesis and mastectomy, which involves the removal of the breast, an organ which defines social construction and identity for the female body. Lorde, in this context, the paper has suggested, seeks the freedom to recover from her illness in her own way. In her autopathography, *Lorde* does not represent only her illness, but makes manifest also her lifelong political work in a clear mode. She imposes her individuality and thoughts on her community, and insists to play socially unsanctioned role in public by using body as text and context for her assertions. In this way, her narrative is a repeat performance of her political life, suitably presented as autobiography, that tries to correct misconceptions, represent the suffering and the dehumanization of breast-cancer patients; and reconstruct the missing humanity which medicine and technology disregard. Like Ryan, Broyard, Sontag, and Murphy who wrote about and humanized their illness, Lorde's autopathography is the performance of the diseased self which brings to light the human aspects of illness, by revising the partial histories written by medical biographers, and by confirming the negative constructions of illness that oppress those sickened by disease.

NOTES

- (1) D. Schiffrin in *The Language of Discourse: Connections Inside and Out* (1990) summarizes the two-fold focus of a discourse: "Discourse itself has often been viewed as both structure, i.e. a unit of language that is larger than the sentence, and as *the realization of functions* [italics added]. i.e. as the use of language for social, expressive... purposes" (98). Lorde's text does not mediate between first and second person parties. It floats free and we as readers can engage with the text and induce facts about the author's intention and/or purpose. Our interpretation does not have to correspond with the author's exact communicative intention. Yet, we assume that the very existence of the text implies intentionality, some claim to significance on which we work to figure out. The topic Lorde addresses (breast cancer) is familiar and, therefore, contextual knowledge is shared with the author (we share lots of common ground), a matter which makes us follow Lorde's argument easily.
- (2) According to Edmund Pellegrino in "The Sociocultural Impact of the Therapeutic Revolution," penicillin was developed in 1941 and came into common use during the fifties (245-66).
- (3) For further information about these educational medical narratives see E. J. Taylor, "The Story Behind the Story: The Use of Story Telling in Spiritual Caregiving," *Seminars in Oncology Nursing* 13 (1997): 252-54; M. Toolan, *Narrative: A Critical Linguistic Introduction* (London: Routledge, 1988); and K. M. Hunter, *Doctor's Stories: The Narrative Structure of Medical Knowledge* (Princeton, NJ: Princeton UP, 1991).
- (4) Arthur Kleinman in *The Illness of Narrative: Suffering, Healing, and the Human Condition* (1988) distinguishes fairly and usefully between illness and disease. He writes that illness "refers to how sick persons and their families, and friends perceive, live with, and respond to symptoms and disability." By disease he refers to a set of bodily symptoms that a physician uses to make a diagnosis and treat a patient (3-5). This essay will assume his distinction between these terms as well.
- (5) Robert de Beaugrande and Wolfgang Dressler define coherence in *Introduction to Text Linguistics* (1981) as that which "concerns the ways in which the components of the TEXTUAL WORLD ... are mutually accessible and relevant" (4). M. Halliday and Ruqaiya Hasan in *Cohesion in English* (1976) outline a taxonomy of types of cohesive relationship which can be formally established within a text, providing cohesive ties which bind a text together and make it coherent (2, 229). Lorde uses these cohesive relationship in her autopathography

(reference, substitution, conjunction, and lexical cohesion)—cohesive devices that contribute to text coherence. Her ideas are relevant to each other, and the sentences are arranged so that they can fit their context. Gregory Colomb, on the other hand, in his article "Coherence" in *Style, Toward Clarity and Grace* by M. Williams Joseph (1990), believes that what guarantees a cohesive passage is following the writer's thread of thoughts, and being familiar with the topic of the passage (48). This is applicable to Lorde's text in the sense that we can easily as readers manage the flow of information, especially that Lorde's syntax is regular. The topic of her text (breast cancer) is also familiar for us as readers.

- (6) This coherent and rhetorically effective writing, however, is almost absent in Lorde's poetry. Many critics, following the works of the literary theorist Cathy Caruth (1995) and the clinician Judith Lewis Herman (1997) relate Lorde's poetic language to the "traumatic" theory. They believe that Lorde is affected by the psychic trauma of disease and by racial and social inequality to the extent that she cannot express such traumatic experiences in narrative, a matter which makes her language in poetry incoherent and disruptive. In this context, Lord uses form in relation to politics; her poetry creates alternative traumatic meanings of communication that reflect her fragmented identity. Dori Laub and Nanette Auerhahn (1993) in "knowing and Not knowing Massive Psychic Trauma: Forms of Traumatic Poetry" address this relation between trauma and narration. They argue: "Much of our knowing is dependent on language—not only our knowing trauma through hearing victims' language, but the ability of victims to grasp and recall their experiences through the process of formulating them in language. Because of the radical break between trauma and culture, victims often cannot find categories of thought or words for their experiences" (288). For example, this is how one of Lorde's poems entitled "Generation II" reads:

A Black girl
 Going
 Into the woman
 Desired
 And prayed for
 Walks alone
 And afraid
 Of both
 Their angers. (*Poems* 81)

As one can see, the syntax is irregular and disorienting, and the overall effect of reading is one of fragmentation. One can argue that the aesthetics of this poem are "traumatic" in that the poem's meaning seems to exceed

language's ability to hold, represent, and narrate it. Clearly, Lorde's life's work as a poet does seem to be stymied by the disease. In the years following her

illness, Lorde wrote coherent and meaningful prose almost exclusively

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