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RESEARCH ARTICLE

Personal/Political: Defining and Redefining Life and Identity Through Autopathographies of Audre Lorde (*The Cancer Journals)* and Srutimala Duara (*My Journey Through Cancer)*

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ABSTRACT

Personal accounts of diseases, as well as testimonies by patients, have taken the power to define diseases away from physicians and given it to patients. Through such accounts, which are now known as autopathographies, the affected describe the struggle of fighting a disease that involves pain; they try to see their changed position in the family and society, and also their changed body conditions, and try to cope with the changes through narrating their experience. They intend to break the silence around words like cancer and make society aware of the actual condition of the affected, and thus help people with similar plights to deal with what they encounter.

Keywords: autopathography; personal; political; healing; bonding

‘Pathography’ is a combination of two words with Greek roots, ‘pathos’, which means suffering or illness, and ‘graphy’, meaning writing. Pathography is defined as a description of disease, trauma, or disability. Robley Dunglison, in A Medical Lexicon: A Dictionary of Medical Science, has defined it as a description of disease, and later seen as a study of the effect of an illness on an individual’s life.

Autopathographies may be seen as narratives on illness and treatment, which are written autobiographically, drawing from one’s own experiences. This narrative is a structural interface of autobiography and pathology. The narrative reveals accounts of not only the clinical procedures but also the psychological impact of the disease and treatment on the affected individuals and their loved ones. There will be a detailed description of the encounter with an illness and the experience of accommodating the illness and its treatment in one’s life. This genre has gained popularity recently in the context of the development of disciplines such as medical humanities. Physicians and medical practitioners typically maintain records of diseases and medical conditions. However, autopathographies enable the patients to take up the narrative position, giving them the power to define their own health condition.

Unlike medical descriptions provided by medical practitioners, autopathographies are subjective in their tone. They analyze the impact of the disruption of equilibrium/normalcy in a person’s life. When a person comes to identify oneself as a patient affected by a chronic illness, one’s sense of body and identity alters. It not only affects one’s self-knowledge but also changes relationships, convictions, and one’s behavioural patterns. Autopathographies also function as a critique of the medical world, pointing out the failure of certain kinds of treatment, a lack of sympathy towards patients, and wrong assumptions regarding illnesses. These narratives are suggested by the patients' well-wishers, as writing them is intended to minimize the stress that patients feel. Like therapy, it helps patients shed unnecessary worries and paranoia, both in front of oneself and in front of others, once they are published.

Autopathographies fall under three main headings: Illness Memoirs, Illness Diaries, and Graphic Autopathographies. Illness memoirs provide a detailed account of the life and experiences of the individual affected. Illness diaries provide detailed discussions of diagnosis and treatment progress, with daily entries. Graphic Autopathographies convey their message through a combination of illustrations and verbal narratives. Testimonial Autobiographies create awareness among readers through open discussions on the fissures in medical treatment. Autopathographies are indeed personal accounts, dealing with subjective experiences in dealing with diseases. At the same time, they can be seen as highly political when they question the premises that lead a patient towards an illness, who profits from the illness, and to what extent profit motives drive people in the medical field.

There have been many autobiographies like Autobiography of a Face by Lucy Grealy (1994), An Unquiet Mind by Kay Redfield Jamison (1995), The Undying by Anne Boyer (2019), and so on. Audre Lorde's *The Cancer Journals* and Srutimala Duara's *My Journey through Cancer* pose questions that address both the personal and political aspects of disease diagnosis and medical treatment. There have been several studies on autopathographies; however, this article, which embraces intersectionality, attempts to examine autopathographies through the experiences of two individuals who have encountered illness and medical treatment from entirely different parts of the world.

The Cancer Journals has three phases. The first one discusses Audre Lorde, who began her writing- 'The Transformation of Silence into Language and Action'. The second phase is about how she experienced the disease as a Black Lesbian Feminist Poet- 'Breast Cancer: A Black Lesbian Feminist Experience'. The third phase problematizes the whole discourse on breast cancer in America, reasons which lead to the disease, the treatment, mastectomy, and prosthesis- 'Breast Cancer: Power vs Prosthesis'. At the beginning of the narrative, she summarises what is to be expected in the following pages. I have tried to voice some of my feelings and thoughts about the travesty of prosthesis, the pain of amputation. The function of cancer in a profit economy, my confrontation with mortality, the strength of women loving, and the power and rewards of self-conscious living. (*The Cancer Journals* 1)

When she begins her narrative, she stresses the fact that women need to look at themselves rather than depend on other people to talk about themselves (2). The anxiety that eats her up, especially in the initial stages of cancer detection, is vividly described (7). She does not believe in unquestioning optimism. As a black woman, she knows that the task to bring in change in the society's attitude towards black women is enormous. In a matter-of-fact tone, she acknowledges that she will not be stopping her work in despair but will continue to fight and hope that the fight will continue even after her death (10).

The detection of cancer in her breast terrified her, but once she had conquered the terror, she could make a firm decision to enjoy life and live according to her own wishes (19). Parting with a dear part of her body, her breast, was pretty tricky for her to accept. More than the thoughts of mortality, the thought of losing her breasts worried her initially. However, later she could take a wise decision to do a mastectomy to save her life, which is more important than her breast (24). Lorde satirically describes the attitude of people towards a cancer-affected patient. Some kept their distance from her, some avoided her. Some expected her to become ennobled by the disease, to be transformed into a saintly person. She felt that she had become a 'pariah'. She desperately writes, 'The status of untouchable is a very unreal and lonely one,...' (41). She tries to transform her encounter with death into a thing from which she can draw power. She does not glorify her path at all. It had indeed been difficult for her to survive through the diagnosis, treatment, surgery, and post-surgery pain. She openly admits all her weaknesses. At the same time, she does not want to get stuck there. She wants to move forward, live life with more zest (45). She loved to return to her work for the upliftment of Black women.

She draws her strength from her African-American tradition. Kwanzaa, an African-American seven-day festival of harvest and the different principles it promotes on each day of the festival, helps keep her morale up. She says, 'Today is the third day of Kwanza, and the principle for today is Ujima - collective work and responsibility. The decision is to build and maintain ourselves and our communities together, and to recognize and solve our problems together.' (*The Cancer Journals* 15)

The Amazons of Dahomey are used as an effective symbol that describes Lorde's condition. She identifies herself with them as they cut off their right breasts to become good at archery. She often thinks of the pain they must have undergone and, with awe and respect, accepts her plight as something like theirs (28). What sustained her through the crisis was the love she received from her women friends and relatives —Adrienne, Bernice, Deanna, Michelle, Frances, and Beth. She found that only they could understand her and stand by her without expecting anything in return. They provided both physical and mental support. The loneliness that a patient suffering from a chronic disease has to face can easily turn the heads of any normal human being. However, with the support of her female friends, she was able to maintain her sanity, confidence, and self-respect (22).

She questions the demand to wear a prosthesis, an artificial breast, after her surgery. Everybody, including the nurse at the hospital, expected her to wear it, as it would make her a normal woman again (41). The stress on this 'normalcy'-women need to appear with all their beautiful contours for others - upsets her. According to society, having one breast makes one less feminine. She problematises the fact that the authorities never probe the reasons for cancer. The use of carcinogenic substances like the fat-stored hormones in beef-feed naturally becomes a licensed product in a profit economy (9). The third phase of her journal addresses the issue of the inadequate treatment of this chronic disease by those who could intervene. The American Cancer Society and its Reach for Recovery Program consider breast cancer as a ‘cosmetic problem’. This naturally comes from the wrong notion that a woman’s identity depends on her physical appearance (48). When life is endangered, it does not matter how one appears in front of others. In a matter of life and death, rather than researching how to prevent cancer, the medical field indulges in creating best-fitting false breasts. Doctors, researchers, medical journals, and everyone in the field are voluble about prosthesis and the effective implantation of artificial breasts. However, they are totally unconcerned about researching the things that cause cancer and how to avoid them. She asks, Why hasn’t the American Cancer Society publicized the connections between animal fat and breast cancer for our daughters the way it has publicized the connection between cigarette smoke and lung cancer? These links between animal fat, hormone production, and breast cancer are not secret. (*The Cancer Journals* 51) She also questions the logic of artificial breast implantation. Other implantations are based on their function, artificial limbs or teeth, for instance, but what function do the breasts serve? Is it only to give a particular shape to the body? (56).

She points at the need to speak out, voice one’s opinion, nothing will be gained with silence, for she says, ‘Your silence will not protect you’ (13). The act of writing itself becomes highly political here. Although these are personal experiences that she shares, she also wants to make it clear for other women who share the same plight that having only one breast is a sign of a fighter, a survivor, and a strong woman (54). Her powerful statements born out of pure experience of pain, give light to any woman who has breast cancer, “Life-threatening cancer and the trauma of a mastectomy can be integrated into the life-force as knowledge and eventual strength, fuel for a more dynamic and focused existence”. (56). She focuses on the threat of depersonalization in portraying prostheses as bringing decent looks. She shares her despair in this treatment of women. As women, we fight this depersonalization every day, this pressure to convert one’s own self-image into a media expectation of what might satisfy male demand. The insistence upon breast prostheses as ‘decent’ rather than functional is an additional example of that wipe-out of self in which women are constantly encouraged to take part. (*The Cancer Journals* 57)

In Srutimala Duara’s *My Journey Through Cancer*, she gives a detailed picture of a woman who had treatment for ovarian cancer. In the foreword itself, she makes her purpose in writing this account clear. Though a personal experience, she noted that down not only to relieve herself from stress and anxiety ensued from illness, but also for the benefit of the readers who may read it. Here, too, the personal narrative becomes a political one. Srutimala Duara was an Associate Professor of English at Handique Girls College, Guwahati. She was also a prolific writer who wrote novels, short stories, and children's literature. As belonging to a privileged class compared to Audre Lorde, the supporting system around her worked more effectively. She receives help in all critical situations and never feels unwanted or forgotten.

In her memoir on her illness, she delved deeply into the experience of different tests that she had to take, including X-Ray, sonography, C125, and MRI. She disclosed the discomforts, anxieties, and uncertainties which each moment gave her. To gain relief and to a certain extent normalcy, her friend Rakhee suggested that she write about her experience. Yes, it was Rakhee who gave me the idea of writing down my traumatic journey of cancer. I realized later how healing this writing had been. I had a purpose. (*My Journey through Cancer* 19) She felt this writing to have a cathartic effect on her. She could keep her mind off the pain (43). As writing was something she loved to do, her journal writing about her experience through the various stages of cancer helped to abate the pain to a certain extent.

She got immense support from her friends Fiona, Angira, Paparee, and Radha. They messaged, called, and visited her frequently (24). They came with her favourite home-made dishes and made her feel loved and wanted. Her own daughter, Neha, stood by her throughout the treatment. Neha spoke less but attended to her mother's needs and was reasonably practical. It was Gopa, her school friend and a cancer patient, who gave Duara different advice. When everyone comforted her to wipe away her tears, Gopa asked her to cry and not to stop her tears. "If you are low, be low. You need not act strong. It is alright to be weak." (43). It was her friends who supervised her daughters' wedding receptions (107).

Hair fall due to chemotherapy troubled her initially. She did not want to lose her beautiful hair. She saw it as part of her identity and thought losing it would change her identity. Her friends and family tried to convince her that she was worrying about something of least importance. However, she slowly comes to understand that she considers her life more important, and in the fight to win it back, losing her hair is just a minor loss. Suddenly, I felt an ache in my heart. Not a physical one, but one caused by images of me not having my hair. Hair that I take so much care of, colouring, streaking, giving it a gorgeous look. (*My Journey through Cancer* 24)

Srutimala Duara tried to see her encounter with cancer as something normal, as any mortal cannot avoid death. However, she wrote honestly about her apprehensions and unfulfilled desires. She looked up to her dear life and wanted to resume her everyday life's journey after the treatment. She examined her altered body and tried to accept the changes it had undergone, marked by stitches and red marks (53). After her treatment and recovery, she was asked to take a tablet that would lessen the chance of a recurrence. The tablet would cost 15 lakhs per year, and she was prescribed to take it for three years. She thought it was better to die than spend so much money on a tablet, so she chose a less expensive one.

Cancer is considered taboo. Nobody speaks openly about it. Srutimala Duara questioned this silence on cancer, which makes the affected terror-stricken. People even consider it a sin (101). According to her, one should consider it as a disease like any other and think of it as curable. Her first stage of cancer treatment left her confident, and with that confidence, she shared her thoughts. When one has cancer, everything is not lost. Everybody has some problem or other. One needs to look at it that way. She kept up this spirit even when cancer recurred twice in short gaps. Though she was worried, she did not lose hope until the end. What she constantly reminds us in her narrative is the need for people to do check-ups constantly and not wait for the final alarm. People often take their healthy bodies for granted and are least bothered about internal conditions until a need arises.

Both the narratives, which can be considered autoethnographies, of Audre Lorde and Srutimala Duara act as texts that politicize the personal experiences of two individuals dedicated to their respective worlds of activity. A disease like cancer changed their lives, and they struggled to cope with the painful experience. For both writers, the process of writing itself was a relief in the chaos of diagnosis, treatment, and the reaction of others. Their narratives create awareness and bring out the truths about the experiences of cancer-affected patients. Neither of these writers glorifies the fight but rather discloses the actual mindset and never claims the survival as their achievement alone. They acknowledge the bonding of women, which strengthened them and uplifted their morale. Initially, both were upset about the loss of their dear feminine attributes, such as breasts and hair. However, soon they correct themselves and see this stress on physical appearance as a trap laid by society, into which anyone may fall. In a profit-driven economy, people try to consider the treatment of cancer and related products as a source of profit. When there are only subtle suggestions in the work of Srutimala Duara, Audre Lorde lays it bare in front of the readers. She considers the business of prostheses is equal to the cosmetic industry, which conforms to the stereotype that a woman's identity depends on their physical appearance. The need to tell everything openly is mentioned by both writers. They also stress the need to give time to think about one's own body.

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