

Audre Lorde's Cancer Experiences

Dr. Dagmar Schultz

Audre Lorde grew up in New York City as the daughter of Caribbean immigrants. She studied at Columbia University, and later became a professor of English Literature at Hunter College. She published 15 volumes of poetry, one novel and several volumes of essays. In 1991, Audre Lorde received the Walt Whitman Citation of Merit which named her as Poet of the State of New York from 1991 to 1993. Her writings and speeches inspired the American feminist, lesbian, African-American and Women of Color Movements of the 1970s and 1980s. She regularly visited Berlin from 1984 to 1992. Her words have become a call for resistance worldwide.

Survival meant for her that early on she found in poetry the form in which to express complex feelings. Survival meant learning from observation and listening to her mother's message: *"You have to understand the basics without words... You have to take what you need by yourself alone... You'll grow strong by doing those things you need to be strong to do."* (Lorde in Schultz, ed., 1983/1991, p. 29, back translation)

This also meant dealing daily with racism and understanding what her mother wanted to protect her from, through silence; making a place for herself as a young Black lesbian in a majority white Greenwich Village of the fifties; being married and eventually divorced; writing a book between two jobs and raising two children with her white woman partner; at age 44 getting breast cancer and fourteen years long struggling despite the illness to love, to work creatively and to remain politically active.

She would introduce herself at readings as "African-American, feminist, lesbian, warrior, poet, Black activist, professor, mother, cancer survivor." Survival meant for Audre Lorde being an outsider – as a lesbian in the Black community, as a mother in the lesbian community, as a Black political radical in academic circles. The guiding motifs of her work derived from these experiences with her manifold identities: to trust her own perceptions, whether pleasant or unpleasant; to speak for herself instead of remaining silent; to recognize her own strengths and power and put them to use; to live with self-consciousness and for the things she chose to do, with happiness, engagement and total concentration; and to love and support women.

In 1987 Audre Lorde moved from New York City to the Caribbean island St. Croix, one of the three Virgin Islands which are unincorporated and organized territories of the United States. Life in New York City had become too stressful. In St. Croix she was part of a Black community that appreciated beyond measure her generosity, warmth and engagement: In St. Croix they gave her the African name "Gamba Adisa" – she who makes her meaning known. When I visited St. Croix, I was surprised to see the hearty and inhibited way people of all different backgrounds greeted Audre Lorde. This environment, the warm climate, the relationship with Gloria I. Joseph as a partner and co-activist with whom she also

shared bee-keeping and honey production did a lot to ensure that, in spite of her illness, her life as a “traveling cultural worker” and her creativity could continue.

Not only because of illness did Audre Lorde stand both at the margins and in the center of her own life. In 1989 hurricane Hugo tore through St. Croix. After a single night, not unlike a thirteen hour bombing, Audre and Gloria came out of their room to find their house half destroyed and the island brown and leafless, as though burned. No water, no electricity, no foods for her prescribed diet – and yet Audre Lorde stayed even after the planes began flying again. She wanted to struggle with the islanders for a new beginning – 90 percent of all houses had been damaged or destroyed – and she spoke out against president Bush's decision to send the army because of the plundering of supermarkets instead of providing the population with badly needed supplies. She contributed to the book *Hell Under God's Orders*, edited by Gloria I. Joseph, which told about surviving Hugo and its ecological, economic, social and psychological after-effects.

In 1980, I met Audre Lorde for the first time at the UN World Women's Conference in Copenhagen I was spellbound and very much impressed with the openness with which Audre Lorde addressed us white women. She told us about the importance of her work as a poet, about racism and differences among women, about women in Europe, the USA and South Africa, and stressed the need for a vision of the future to guide our political practice. On that evening it became clear to me: Audre Lorde had to come to Germany for German women to hear her.

I was teaching at the John-F.-Kennedy Institute of Northamerican Studies and could propose Audre Lorde as a guest professor. In 1984, Audre Lorde came to offer courses on Black literature and creative writing at the Free University of Berlin.

By then, I had published the book *Macht und Sinnlichkeit (Power and Sensuality)* with texts by Audre Lorde and Adrienne Rich, and Audre was involved in readings and in meeting Black Germans whom she encouraged to organize and to write.

Life with cancer – this meant for Audre Lorde living with heightened consciousness and understanding death and dying as an integral part of her life. My friendship with Audre Lorde was strongly conditioned by her struggle with cancer. When she arrived in Berlin, I suggested that she visit a woman doctor, an anthroposoph.¹ Yet I had not counted on being the one who had to tell her what the doctor found: liver metastases, a diagnosis she had already received by her doctor in New York, but not talked about. Audre decided to undergo a naturopathic treatment of her cancer illness – a treatment with mistletoe and homeopathic medications that was not available in New York. This meant that she often had to defy the counsel of her New York physicians. I experienced her struggle close-up: she neither denied her

1 Anthroposophy is a philosophy founded in the early 20th century by the esotericist Rudolf Steiner that postulates the existence of an objective, intellectually comprehensible spiritual world, accessible to human experience. (<https://en.wikipedia.org/wiki/Anthroposophy>)

illness, nor did she place it in the center of her life, but got to know her body better and better, striving to overcome its weaknesses and limitations.

Audre returned to Berlin almost each year for several weeks or months for her work with her publications and with Black Germans and the white women's movement. During those times I learned a lot from Audre in the way she dealt with her illness. In an interview I made in 1984 together with a friend, Erika Fink, on her cancer experiences, several aspects were especially important for me.²

How Audre dealt with the fact that she had cancer

Just as Audre did everything with intensity and a thirst for knowledge, so too, did she approach her illness: she knew more about cancer and therapeutic methods than did many medical-school trained doctors, and she gave her experiences to many women throughout the world.

"I had decided I wouldn't do radiation if my nodes were clear. My doctor had no opportunity to make a suggestion regarding the immune system, this was still in the stages of experimentation.

An oncologist I visited afterwards spoke about the immune system only in terms of dietary restrictions, implying I should stay away from fat. There was a lot of material on the relation between animal fats and cancer when I started reading by myself, not just in the Journal of the American Medical Association. He was as close to a holistic doctor as I had met by then."

DS: What is the limbic system?

AL: There are three parts of the brain, the limbic system represents the most primitive structure in control of involuntary muscle. We now know that we can affect the limbic system and this is what biofeedback is all about, training yourself to affect involuntary responses. You may strengthen the limbic system to fight extra battles through visualization. There is however an ongoing oversimplification I have found in medical journals which is infuriating; that no happy person ever gets cancer."

How Audre dealt with the medical system and with acquiring knowledge

After meeting an anthroposoph doctor in Berlin, Audre decided for a naturopathic treatment and felt empowered to withstand the school medical therapies she was to undergo in New York. When she returned to New York and tests showed that the metastases had reduced, the doctors called this a spontaneous remission and did not

² Schultz, Dagmar: "Audre Lorde on Her Cancer Illness." In: Joan Wylie Hall (ed.), *Conversations with Audre Lorde*. Jackson: University Press of Mississippi, 2004, 132-142.

acknowledge the possible results of the treatment. But Audre decided to continue the therapy in Berlin.

“I have dealt with doctors who laid the most bone-crushing pressures upon me, to have biopsies for instance. They threaten you not only with the fact that you might die but also for being stupid and emotional. They withdraw their support by claiming I won't be responsible for this. It is frightening. The only answer is to learn to withstand certain pressures in our lives by recognizing the other forms of pressure we are always under. The ways in which we might deal with breast cancer, as well as how we deal with doctors and physical crisis, are composed by how we confront other areas of our lives. When you teach kids how to deal with peer pressure it becomes a vital part of keeping them away from hard drugs, they are free to make their own decisions once you have taught them. The process of encouraging women to make their own decisions is ongoing, but we must work very fast. I do say this urgently for women who do not have breast cancer; we need to develop a larger stance on our bodies and all areas of our lives so we may learn to say no and defend our own interests. This is very hard to do.”

DS: We haven't talked about diagnosis; the way medical personnel dealt with you and the options you had.

AL: The first time I was instructed to have a biopsy I was told I had an 80% chance of malignancy from the contours and so on. I did get a second opinion from a breast cancer surgeon in New York who told pretty much the same thing.

DS: Both times you went to a surgeon.

AL: I went both times to a surgeon, after having gone to my regular doctor who is a gynecologist as well as the radiologist who did the mammography. The choices were breast surgeons from then on. These were the only people I knew, who had been recommended to me, who dealt with breast tumors. My gynecologist had done what she could, which was to recommend a radiologist and the radiologist confirmed there was something there. At that point I did not have enough knowledge to do anything else. I started reading whatever I could about it. I started thinking about what it meant, how I felt, the terror, the sense that I had to get more information which was difficult to find. I chose my surgeon because he gave me and Frances the most time in terms of explanations, answering questions, going over those questions again. That was Peter. He was the doctor who recognized the relationship between Frances and I and treated her as my family, as my closest.

I saw three doctors in all. The reading I did in the meantime helped me

consider what I would do in case my tumor were malignant. I knew I had to keep control over this space of time. I had already decided I would understand the procedures before any further operation. I started thinking about alternatives, as much as I could back then, also about radiation. I felt strongly that chemotherapy and radiation were bad news, a lot came from things I read. I read a lot of medical material in any case.

I am interested in spreading information about alternatives.

How Audre built up the power to confront this crisis in her life

For me, this attitude was extremely important. Especially the focus on having to be aware of how we move and act in our daily lives. In Audre's words:

*"I would not have been able to overcome had I not done similar kind of work previously in my life. I would not have been able to decide against radiation if I hadn't come across other decisions in my life. In other words, we build and become strong by doing the things we need to be strong for. We do them little by little and it builds up. This is why it is important to speak to the cab driver who makes insulting remarks about women. Some days you won't bother because you may be doing something else, sometimes you notice and think well, maybe next time. That is only part of making ourselves strong. One thing comes after another. **We meet breast cancer like we meet every other crisis, out of a composite of who we are.** It all comes back to a certain quality of living, a certain way of learning how to move through the world. It is not even about learning to move through the world in specific ways—God knows I see women moving through all the time in ways I wish I could and know I can't, or else moving through the world in ways I think are terrible. One thing comes across in all those different ways, it is a certain determination to use whatever we have, I recognize this; a certain kind of development of personal power. Nothing says women cannot embody evil. I am not even dealing with that. I do believe that helping our power come into being is positive and good.*

I am talking about why I believe empowered women are important. It is not because I think women cannot embody evil or act incorrectly. It does not mean that I can't envision a time when my enemies are women, what I am saying is that I will take my chances."

How Audre dealt with social and political aspects of breast cancer

I was very impressed by her political analysis of the causes of breast cancer and of the consequences of breast surgery. Audre emphasized the fact of environmental causes of cancer. And she pointed out that women were to wear prostheses not only because they themselves wanted to do so for various reasons, but because society does not want to be reminded of possible reasons for (breast) cancer and because women were expected to function quickly after a breast removal as partner, mother, housewife, worker. Audre Lorde had always been on the offensive with her illness, not without fear and anger, but determined to keep control of her body and to continue leading her life as she conceived it should be lived. Already in 1978, after the amputation of her breast, she had begun designing jewelry and clothing for women who refused a breast prosthesis, a truly positive approach for one-breasted women. She also made it clear that Black women cannot be expected to wear pink prostheses – there was no provision for other-colored prostheses then, and I do not know whether that has changed.

“A lot of responses to the question of prostheses in work environments vary from two positions. One (gasp); you are going to ruin your body – arguments of uneven anatomic proportion, posture, which are of course bullshit. None of these deal with the fact of large-breasted women whose breasts are unequal in weight. No one deals with the lifetime effects of baring babies on our hips. On the other level there are those who claim there is so much discrimination against women to begin with, which leads them to avoid telling their employers about breast cancer. They are terrified of people's attitudes or that they might lose their jobs. I hear that, except I know that the way to fight this stuff is not by pretending it didn't happen. I know this because I was born Black and a woman in The United States of America. That really is like saying, the way to combat racism is by pretending you are white, as if mobilizing in this way were the only thing to make it yield. But there will always be women who can, who are unassailable, I am talking to them.

What I have said to women in the The States applies to women here in Germany as well; you have to be aggressive about getting information, speaking up to women's institutions, telling them they have a responsibility to publish articles and have them around, impress upon women that there are alternatives – so this becomes knowledge a-forehand in our consciousness in the event a lump occurs.

Cancer is a woman's concern. Breast cancer is a feminist concern. Cancer is a feminist concern of the 21 year-old feminist who doesn't know it. Look

how long menstruation was a secret little thing we didn't talk about. We thought, we are going to build a future, we have a feminist vision, we have a lot of work to do, but nobody mentioned we should make sure there are always Tampax in the bathroom. It is as if we were cut off from certain parts of our lives. Breast cancer is an issue we cannot afford to be removed from because it is rising. It is a feminist concern because there is work that can be done by us as informed women.

The work I did, finding out about cancer during that preparatory period, not only informed me but also enabled me to make decisions when I finally had to deal with my condition—it also made my head work around these terms. Cancer is a political fact and it is necessary for us to see what some of those implications are; the possible relation between fat and breast cancer, the kinds of pollutants that are carcinogenic, these are things we need to attend to.”

Audre's honesty in communicating the weaknesses she experienced

“I wasn't writing poetry at the time of my sickness. It was a terrible time for me because of this, in addition to cancer. I knew the two weren't unconnected and it was quite severe. I write about this in “The Cancer Journals.”

I would like to examine the real fractures that happened throughout that three-year period after cancer. When Michaela Rosenberg (the doctor in Berlin) mentioned six years being a short time after this form of assault on the immune system, it seemed that for the first time someone was dealing with that. In the U.S. you get a month and then you are good, but it took me three years and I kept wondering whether I was doing something wrong. I know that for three years I was in a desperate battle, I knew it all through my system and wanted to chronicle it in some way.”

DS: The recuperation period does not mean anything regarding how you feel.

AL: That is right; you're fine and uplifted, and new prosthesis, and new hairdo. I didn't write a word of poetry and people got tired of me during those three years. It was like they wanted to say enough is enough. I was saying no, enough is not enough, this is my life. Sometime I will try to put that down in writing because I think it might be useful to other women.

I was in a position to recuperate, I could get a leave of absence from Hunter and Frances (Audre's partner) could carry me and the kids financially for half-

a-year. Most women with breast cancer are not in that same position economically, most Black women who have breast cancer certainly aren't in that position—how will they touch the core of what I am saying in a way that can be at least sung?

These are the questions I want to raise even in private spaces.

DS: There is also a confrontation with the fear others might have of illness, their challenge to participate in your struggle.

AL: Are you talking about the way people either ignore or objectify their fear?

I had a lot of respect for my landlady. I told her my forthcoming book was titled *The Cancer Journals* and she could immediately tell me that cancer was one of the things she had an absolute terror of. I told her something about that being the reason why I wrote the *Cancer Journals*."

DS: Did you feel your position was unassailable?

AL: I thought it was pretty unassailable. I can't really see the University of the City of New York firing me because I had breast cancer, or because I didn't wear my prosthesis. My students were a little upset and some people even left my class. I think there were people who thought I was very bizarre, but there are always people thinking I am bizarre anyway.

I feel, Dagmar, that I often go through life feeling unassailable. I feel vulnerable and completely unassailable. I feel both things at once. The reality is somewhere in the middle, meanwhile here I am operating as both. Usually I manage to bungle my way through (*laughing*). I see very clearly how I live."

Just as Audre Lorde revealed her lesbianism, she openly dealt with her breast removal. In her book *The Cancer Journals* she wrote: "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 self-conscious living." (Lorde, 1980, 9-10)

Her last summer Audre spent with Gloria, Ika Hügel-Marshall and me in Berlin in our apartment. This season showed us that her life would not be much longer. Ika and I learned how to talk with her about her coming dying. At the same time, we also talked about developments in the women's movement and political events.

Her last reading took place in our apartment. She read her newest poems in which she was addressing death. A recording of the reading, which she dedicated to women in Soweto, was sent to South Africa. A few weeks later, Ika Hügel-Marshall, May Ayim and I flew to St. Croix to be with Audre in her final hours.

In the year 2000, eight years after Audre Lorde passed, I had my first cancer diagnosis. Cancer of the uterus. I went to three doctors to assess what operation to have made and then made a decision. If I had not known Audre I might have taken

the advice of the first doctor which turned out not to be the preferable one. Two years later I had a second diagnosis of *morbus hodgkins*, a lymph node cancer. Both times the doctors told me that I picked "the best one of all cancers" on account of the degree of chances of healing. With the second one I was confronted with deciding on a therapy. I took some time to inform myself especially since even Audre's naturopath advised me to choose chemotherapy and radiation.

Ways in which having accompanied Audre all those years up to the night of her passing in St. Croix helped me with my cancer illnesses

Exactly six years before her death Audre wrote in her diary: "Living fully – how long is not the point. How and why take total precedence." (Lorde, *A Burst of Light*, 126) The how and the why meant living with intensity on the front lines. This joy in living and the deep commitment to do as much of the political work she felt she was on this planet for – these were experiences I had with her which gave me strength to deal with two cancer illnesses and maintaining my life purposes. Certainly the fact that I "picked the best ones" also helped.

Another helpful aspect was important: I had been a close friend of a person with cancer and seen how different that position is to that of the person who has cancer. Now I could understand how my partner felt. When you get the diagnosis you know you have to deal with it. Your partner finds her/his self in the position of struggling with supporting you and with her/his own fears. It is important for partners, family members, friends to get support for the situation they find themselves in.

Audre wrote about her illness, because writing was her means of processing her meeting with death and breaking the taboo on revealing the environmental causes of breast cancer. And she hoped that her words would "serve as an encouragement for other women to speak and to act out of our experiences with cancer and with other threats of death, for silence has never brought us anything of worth." (*The Cancer Journals*, 10) I published her work in Orlanda Frauenverlag and made the film "Audre Lorde – The Berlin Years 1984 to 1992" in which she also addresses her cancer. Her energy has empowered me and still does so.

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Audre Lorde in Berlin Online Journey. www.audrelordeberlin.com