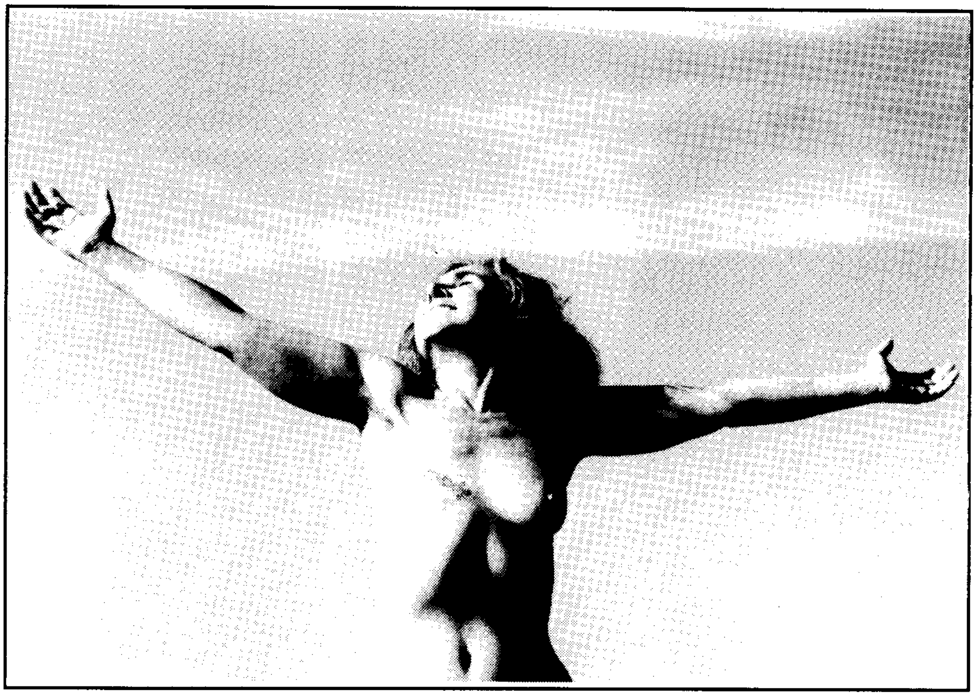
Women With Cancer and the Meaning of Body Talk

by Cynthia Mathieson

L'auteure discutte des problèmes associés avec le terme "image corporelle" pour les femmes atteintes d'un cancer. Des récits de patientes atteintes de cancer illustrent deux difficultés importantes: premièrement, le langage médical tait la voix des femmes et deuxièmement, le cancer continue à stigmatiser la personne malade.



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In over five years of conducting in-depth interviews with persons with cancer, probably no concept has troubled and intrigued me more than "body image." This is not because I lack a language to talk about and to professionally evaluate body talk. Having been trained in health psychology, medical and psychological jargon are readily available to me. Research on body image and women with cancer, as well as the emphasis on breast cancer and impaired body image, are two examples of this language in its research home. Here we find repeated references to the psychological impact of cancer, breast loss, distress, and impaired body image. In some studies, one has the sense that body image is much like a personality trait, with some people having more or less of it. In addition, much of the body image literature seems to concern women, from issues of chronic illness to eating disorders. It appears, then, that body image has been cast as a woman's problem.

Body image means different things in different studies. Most body image questionnaires ask individuals to agree or disagree with statements as to how they view their bodies. For example, in some studies of cancer patients, women might be presented women with a body image checklist which includes scaled responses to the following types of questions: (a) I do not like my nude appearance, (b) I do not like my dressed appearance, (c) I have problems with sexual relations, (d) I feel self-conscious in groups of women/men, (e) My body has a pleasant smell. But what do these statements mean to a woman who is living with the ongoing physical, psychological, and social demands of cancer? In fact, what does a low score on a body image scale really mean?

The women with cancer who have shared their stories with me clearly seem to be speaking with a voice quite different than that of medicine, psychology, and measurement technique, when they try to describe body changes resulting from their cancer diagnosis. I suggest that physical changes in bodies signal a rite of passage from good health to illness. Within this rite we may witness physical assaults such as surgery, chemotherapy, radiation therapy, loss of bodily function, and hair loss. These are disease-related events with a medical language. However, women speaking for themselves about their illness have suggested a far richer level of description to this rite of passage. The personal meaning of these changes is paramount: they signal to the person herself, and to the individuals' social radius, that she is a cancer patient. In the context of lived experience, the result is that the social space one inhabits is disrupted so profoundly by a life-threatening diagnosis that identity is threatened. Taylor refers to identity as the "...indispensable horizon or foundation out of which we reflect and evaluate as persons," and that to lose this, "...is indeed a terrifying experience of...loss" (125). Since healthy and ill persons alike are embodied, it seems that identity is inextricably bound to our taken-for-granted bodies. Under illness conditions, however, body signals create increased awareness and they take on new meaning. The idea that there is a body image which stands apart from the lived experience, much like an image which might be reflected in a mirror, provides little insight into the cultural and social meaning of cancer.

When I have interviewed women with cancer, I usually try to construct, with the participant, the context in which she finds herself once diagnosed with cancer. I tape record the interviews, which constantly reminds me that I have been privileged by my participants to share the details of their suffering which may remain unspoken to even those close to them. The interview includes an intended focus on the biography of the individual, and the ways life has changed as a result of the illness. I ask specific questions, one of which is "What is different about your body since your diagnosis?" Not surprisingly, issues about the body appear repeatedly throughout the interview, in response to other discussion. I say this is not surprising because I do not conceive of the body issue as separate from other parts of the person's narrative. In fact, this highlights one of the problems we encounter with traditional medical research, that body talk is incidental to the focus on disease. Things may be done to the body to try to control the disease, but talk is rarely encouraged within a medical setting which authenticates the ill person's experience of a body which is being transformed. In contrast to the medical scenario, I have come to believe that body talk is central to the illness experience, and that to relegate it to the periphery, marginalizes what it is like to live with a chronic, life-threatening illness such as cancer.

Many notice the discrepancy between their body talk and the language of health care providers.

This essay draws on the interviews of 60 women who were interviewed from 1989-1991 while I was completing my doctoral degree. I intentionally interviewed a heterogeneous group of women with cancer, although within this larger group there existed a sub-group of 34 women with breast cancer. These were women of varying ages (from 31 to 71 years old), with many different types of cancer, and dates of diagnosis ranging from the previous two months to five years. Some were close to diagnosis, some were terminal, and some felt that their cancer had been cured. I interviewed women who had undergone all types of treatment regimens. The variety was important to me in establishing a broad descriptive picture of women's concerns. The interviews I continue to conduct to date are consistent with the concerns which will be identified in these interviews. If anything, as I continue collecting patient stories, I have had the opportunity to refine my thinking about why cancer is such an identity altering experience for women, and the meaning of body changes within this situation.

The language of medicine

Lacking any other language with which to describe the illness, women sometimes confine descriptions of their cancer to medical terms: they can give me the proper name of the disease, the statistics for survival rates, the names of complicated chemotherapy's. But this knowledge has always been gained at a price. Many notice quite clearly the discrepancy between their body talk and the language of health care providers. One woman with breast cancer spoke to this discrepancy when she said:

> *In my opinion, nearly all the professionals that I've come across have been very concerned about...the loss of the breast, and I couldn't care less about that, I mean, my life is far more important than the loss of the breast, but they [the physicians] put a great deal of weight on...this blob of skin being removed, as if part of my personality has gone with that breast.*

The type of communication engendered in physician-patient relationships is often dependent upon learning and using medical terminology, which is the language of the health care provider. Yet, there is another language of the meaning of body changes which forms the real voice of women. This is a voice which struggles to be heard in establishing oneself as a partner in health care. The following excerpt comes from an interview with a 62 year old woman who was receiving chemotherapy treatment. She is speaking about why she refused at one point to return to the clinic for treatment. I think it is a good example of the enormous difficulty women face in speaking to their physicians, many of whom are men, about their bodies and the effects of cancer:

> *I got mad and I said "That's it.... They've insulted my body and I am not going back".... Even if you had three hairs and you lost those three hairs, it would be devastating... because you walk around, and nobody knows you're ill.... Now when I go to the shopping centre, and everybody knows there's something wrong with me, that I'm ill, that I must be under some type of treatment.... Doctors can't appreciate that; they're scientists. The true feeling of that.*

One might simply ask why this woman did not speak directly to her physician. At this point, it is important to keep in mind the expectations for patients to turn over their bodies for treatment, and the enormous power attributed to those who are going save one's life. Expectations for patient behaviors include asking "acceptable" questions and having a positive attitude. A 43 year old woman with metastatic (recurrent) breast cancer expressed her distress with having to argue with her physician repeatedly over the possibility that her can-

Health care providers are often insensitive to the women's own perceptions of body changes.

cer had returned. Her own body signals had been that it had, and she turned out to be correct. She said:

> *I wish I could talk to the doctors better and wouldn't be so intimidated.... Just because you're asking a question, they think you're being negative.... After the second time, I didn't have that much faith in the diagnostic equipment...and then I got a long lecture on being positive from him.... Does that mean I'm being negative, as soon as I ask a question?... And that's the only time I ever really got mad at a doctor, because he was giving me this long lecture about being positive, and that I wasn't positive, and I get tired of hearing that....*

The language of medicine is not the authentic voice of the ill person.

Despite recent calls for women to take control of their health, health care providers are often insensitive to the women's own perceptions of body changes. Moreover, the concerns of patients in decision making for treatment may not be considered, despite the fact that recent medical research has stressed incorporating the patient's viewpoint into this process. A 64 year old woman with breast cancer relayed the following conversation with her physician:

> *I dug my heels in and said.... "If you're asking me to take radiation why did I not have the choice of having my breast removed, of having a mastectomy".... "You would want a mastectomy?" And I said, "Well certainly, the history in my family of breast cancer," and I said "It wouldn't matter," and he said, "Well, wouldn't it bother you to have your breast removed?" I said "Absolutely not, I'm 64 years old," and he nearly fell on the floor.*

The above excerpts illustrate to me that there can exist pronounced discrepancies between the health professional's vocabulary about body image and the issues which comprise the actual body talk of women with cancer. The language of medicine is not the authentic voice of the ill person when she speaks about her body. Institutionalized medicine in general has not created a space for that voice. One woman in my study summarized this as the following:

> *To express concerns, it's just not part of the process, like you don't go in and have chemo [therapy] and talk about the experience....People shouldn't have to go through six months of chemotherapy and be afraid to look at the cancer.... They're not just patients.... We're not just there receiving treatment.*

Yet another striking example of this discrepancy is seen in how women with cancer experience the stigmatizing effect of their illness.

Stigma

Treating cancer, by treating the body, is a priority for medicine. The psychological and social ramifications of the cancer, or the treatment, however, must often be borne in a singular fashion by the patient. The problem is that the body now signals to the external world that one is a cancer patient. We hear in women's stories that the loss of hair acts as such a signal. Loss of weight during illness can also assume this role, as can a permanent scar from surgery. Breast cancer women, who had been permanently "tattooed" for the exact delivery of radiotherapy, also referred to this procedure as a signal.

There were many reports of friends, family, and co-workers acting differently toward the ill person in the presence of these signals. In other words, the body's image now acts as a stigma which is used to discredit or stereotype the individual. For example, we hear one woman, herself a person with breast cancer, talking about one for her friends:

> *I travel in a group of women, and one of these women had serious cancer, and I saw her the other day...and I looked at her and I thought—I couldn't—think anything else of her, I couldn't think of what a fabulous person she was. I mean, she had in capital letters, written from the top of her head to the bottom of shoe, CANCER, and I couldn't get beyond that to see the person she was. It was terrible....*

Not surprisingly, women made reference in interviews on many occasions to their bodies being contaminated, broken, or damaged. Even stronger statements included being betrayed by one's body, feeling filthy, or having leprosy. The psychological effects of this stigma are pronounced; women reported that they felt like different persons as a result of some of these experiences.

> *I haven't got leprosy...I've got cancer. So fine, I won't get close to them [family and friends]....Before that [cancer], I was out, I was active, I was a participant....I don't feel that I'm part of the human race anymore, I don't feel that I have anything to contribute.*

An additional point about stigma is that it continues to exert its effects long past the point when the body has been treated for active disease. Here is a young women speaking about the long term effects of her bilateral mastectomy, which had occurred a year before the interview:

The body's image now acts as a stigma which is used to stereotype the individual.

> *I ended up feeling so odd, and so weird, so abnormal I guess, that I preferred being alone....I don't feel free to let people know how I feel. I*

> *feel I have to hide it, like somehow all these things are shameful.... Somehow I don't ever see myself fitting in.*

Why body talk is important talk

First, I would like to suggest that there is no abstract body to be viewed or measured. There are only ill persons living with ill bodies. This should caution us that "body image" terminology cannot access the personal world of illness. Any interchange with the social world we inhabit can remind us that being ill carries a certain stigma. Becoming healthy is not a simple matter of bringing one's impaired body image back on line with what is normal, or expected, and then carrying on as if nothing had happened. Second, body image seems to have been cast as a woman's issue. This is problematic. Both men and women have bodies, healthy or ill. To cast body talk in the terms of "woman talk," marginalizes the meaning of illness and the experiences of women. It may be that men and women who are ill talk in different voices about their bodies, but in this case we would be forced to look at how and why men and women have different illness experiences, and the extent to which they are given avenues to articulate these experiences. Third, what is clear to me from the patient narratives is that the actual body talk of patients is important talk. Women speaking about their bodies need to articulate the meaning attached to dramatic body changes. This is a point of decision, as it were. One can adopt medical language, turn over one's body for treatment, and become an observer of one's own life with cancer. On the other hand, if women are really to take charge of their health, they must not step aside and let professionals and researchers talk for them. It seems to me that body talk is a good place to start.

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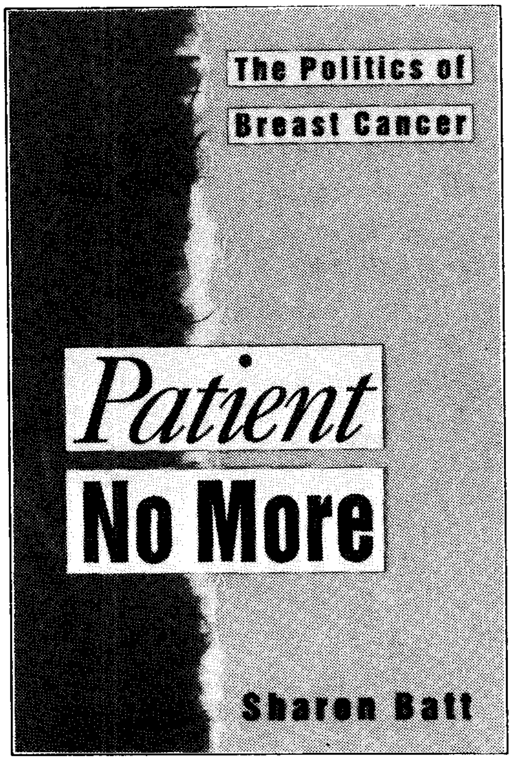

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