Women With Cancer and the Meaning of Body Talk

by Cynthia Mathieson

The author discusses the problems associated with the term "image corporelle" for women affected by cancer. The stories of patients affected by cancer illustrate two important difficulties:

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 to relegate it to the periphery, marginalizes what it is like to live with a chronic, life-threatening illness such as cancer.

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 chemotherapies. 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

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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-
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 breasts 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 breasts 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:

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 her 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]...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 moment when the body

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

has been treated for active disease. Here is a young woman speaking about the long term effects of her bilateral mastectomy, which had occurred a year before the interview:

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.

References


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