

## The Wounded Body in Public Space: Voices of Breast Cancer Survivors

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### Abstract

Breast cancer has been a taboo subject and stigmatized for a long time and still is in many societies. However, in recent decades breast cancer has become a public issue in some countries. It is no longer the patient's "own" disease or that of the medical profession, but also belongs to beauty companies, the clothing business and other commercial enterprises. All want to be a part of the public discourse and profit economically from breast cancer. Following Peter Conrad's formulations, this paper first discusses the "outsider perspective" on breast cancer and focuses on how society shapes this illness. Based on qualitative research conducted with German breast cancer survivors, the second part of the paper focuses on their "insider perspective" and especially how they deal with their private body in public. In this way the paper seeks to highlight and analyse both cultural attitudes towards the body as well as the manner in which breast cancer is socially constructed.

**Keywords:** Breast Cancer; Chemotherapy; Body; Physical Activity; Public Space

## Introduction

In contemporary consumer culture physical changes having negative implications and connotations are not allowed to leave any traces on the body; they are often suppressed and hidden by clothes, diets, exercise and plastic surgery to present a young, fit and thus supposedly healthy and flawless body (Wenner, 2001) [1]. The body is no longer considered to be the consequence of destiny, but rather something to be manipulated, constructed and reconstructed. In the case of illness-related bodily changes and restrictions, culturally dominant bodily ideals can be threatened and, as a result lead, to deep emotional problems. One such illness that is a considerable threat not only to a woman's life but also to her bodily ideal is breast cancer which, according to a Gallup-Study, is the most feared disease among women, although many more women die of heart disease (Von der Lohe, 2002) [2]. Mamma carcinoma is the most common malignant tumor in women, leading the statistics of the cancer-related causes for death in western societies; about every 8<sup>th</sup> to 9<sup>th</sup> woman is afflicted with it. This paper refers mainly to Germany where, in 2008, almost 57,000 females were diagnosed with breast cancer; in the United States the figure is around 190,000 women. In Germany every year about 17,500 women die of this disease; in the US, 40,800.

No other disease is so connected with bodily ideals and femininity, as is breast cancer. It was a taboo subject and stigmatized for a long time and still is in many regions of the world. However, throughout the last decades in some countries breast cancer has become a public issue. It is no longer the patient's "own" disease or that of the medical profession, but also belongs to beauty companies, the clothing industry and other enterprises, all of which want to be a part of the public discourse and profit economically from breast cancer. This new openness reveals both advantages and disadvantages for afflicted women. On the one hand, they can more easily talk about their illness and the problems connected to it. On the other hand, breast cancer has become re-constructed socially and culturally, to be commercialized and exploited by society.

To better understand how breast cancer survivors see and perceive their changed body, I use the American sociologist of medicine, Peter Conrad (1990, 5), who writes that it is "not sufficient (...) to only present descriptions on how people experience and manage this or that illness (...)," but also to ask what

influence the illness itself has on a patient. Conrad refers to both an outsider and an insider perspective of illness. This view is coined from medical and social dimensions where the sickened are often moved to the background. The insider perspective pertains to the subjective experiences of the sick person and reflects the feelings of the lived body:

„Outsider perspectives view illness from outside the experience itself, minimizing or ignoring the subjective reality of the sufferer. They see the patient, disease or illness as an object or something to be affected. They are often deductive in orientation and adopt medical or social theoretical questions as their central concerns. In contrast, an insider's perspective typically focuses directly and explicitly on the subjective experience of living with and in spite of illness. It focuses specifically on the perspectives of people with illness and attempts to examine the illness experience in a more inductive manner. The conceptual or theoretical issues are not always a primary concern.” (Conrad, 1990, 1259) [3].

In keeping with Conrad's argument, in the following I first discuss the public or outsider perspective of breast cancer and show how society shapes this illness, by starting with the afflicted organ, the breast. In examining the social construction of breast cancer I use Erving Goffman's elaborations about Stigma. Then, based on qualitative research conducted with breast cancer survivors, the second part of the paper focuses on how they present their private body – a body that shows certain scars and wounds – in public. In this way, afflicted women are given a voice and their insider perspective is revealed. The interviews were conducted in Germany with German women. Since social scientific discourse about breast cancer is still developing in German academic publications, the paper refers to Anglo-American research, yet this does not always represent the German situation accurately. Therefore in terms of the women's responses, readers might notice cultural differences about how the body and how breast cancer are socially constructed. These lead to different behaviours and customs when it comes to an aspect that I call the "private body in public space" – how breast cancer survivors feel about displaying their naked upper body in public places such as locker rooms, saunas and beaches.

## The Breast: Symbol of Femininity, Fertility and Sexuality

Body parts and organs play a significant role in social discourses and power struggles, especially when they relate to a woman's body. What makes breast cancer different from most other diseases is that it is connected with the female organ: the

breast, an organ replete with symbolism. Through its many meanings it has gained more public attention than any other organ and none other has been exploited to such an extent in the western world.

Following Kafka's "Metamorphosis," American writer Philip Roth describes in his novel *The Breast* (1972) the transformation of the 38-year-old protagonist and narrator, David Kepesh, a professor of literature, into a 155-pound female breast. This organ is supernatural in size, soft and youthful. On being touched, it reacts with sexual pleasure. This breast is not only a body part, but it becomes the new body of the narrator. I do not want to analyze this unnatural-sized breast, but, what is obvious in Roth's novel is that the breast is an organ that extends forward through its shape, reaches out to contact the world, and has an inner life as well. The German physician Ingrid Olbricht (1989, 102) describes it as an "organ of relationship" which communicates and is, in many ways, important for interpersonal relationships.

Because of its great potential for expression, the breast has become the symbol of femininity, fertility, and sexuality. At a very early time in their lives, girls learn – or, rather, societal norms help them learn – that their breasts have something to do with their sexual identity. Here, especially clothing functions as a gender marker. For instance, in the United States – unlike in Europe where it starts with puberty – very young girls, although they are years away from developing breasts, are already expected to wear a bikini top at the beach, and are restricted in the way they dress and present their body publicly (Berger 2004) [4]. This hiding of the breasts from the public view has to do with the fact that in the western patriarchal world they are objects of beauty and have an erotic dimension that makes them into an object of sexual desire, which should not be shown too openly.

The value of public breasts diminishes with age. Iris Young states: "Flat, wrinkled, greatly sagging, the old woman's breasts signify for the dominant culture a woman no longer useful for sex or reproduction, a woman used up." Contrary to the western world, in some other cultures women with wrinkled and sagging breasts are venerated. They symbolize motherhood, wisdom and life experience (2005, 79). Anthropologist Margaret Mead observed that there are women among some primitive tribes who stretch their breasts to take on a hanging form (1992, 203).

These few examples show that breasts underlie a strong cultural influence and carry a "cultural weight" although they are part of the intimate sphere of a woman, as Latteier (1998, 111; 164) [5] writes. She goes further; in relation to the western world,

she speaks of a "cultural breast obsession," an argument that is supported by Marilyn Yalom, author of *A History of the Breast* (1997) [6], who summarizes the functions of the breast as follows:

From outside, the breast represents another reality, and one that varies in the eyes of each beholder. Babies see food. Men see sex. Doctors see disease. Business sees dollar signs. Religious authorities transform breasts into spiritual symbols, whereas politicians appropriate them for nationalistic ends. Psychoanalysts place them at the center of the unconscious, as if they were unchanging monoliths. The multiplicity of meanings suggests the breast's privileged place in the human imagination. (Yalom, 1997, 183) [6].

Especially in western patriarchal culture women are judged from the beginning of their puberty until the end of their lives by the size and appearance of their breasts (Young, 2005, 125) [7]. Thus, it is not surprising that when they change their appearance in the process of puberty, childbirth, aging, or illness, and are no longer in accordance with the norms set by themselves or by society, many women find their physical aesthetic and body image threatened, as is witnessed by the great number of breast reconstructions. Here it should also be mentioned that breast reconstructions after a breast amputation (mastectomy) also reflect a cultural influence. There are no exact numbers; only tendencies can be shown. About 17 percent of American women chose an artificial reconstruction after a mastectomy in the years 2000-2002; in the United Kingdom it was 23 percent in 2008, whereas in Germany a regional study (2007) showed that only 13 percent decided for this procedure. In the US there is a tendency by various medical organizations to make breast cancer patients believe that "Most women who had breast reconstruction are glad they did." However, a study by Kaspar (1995) shows that this cannot be generalized at all [8].

The intense awareness of the breasts is also expressed by a breast cancer patient shortly before her surgery: "I love this part of my body," although it is evident that the existence of her breast as she knows it is in danger. She goes on: "I would love it still, love it always" (both quotations cited in Block 1998, 126) [9]. For some women, their body image is so strongly connected with the breasts that they refuse to have a mastectomy when diagnosed with cancer, even if this means certain death. Lerner (2000: 157-158) [10] cites a woman who said, before her surgery, "I go whole, in one piece;" and another one who stated: "I came with two, I'll go with two." The question rises as to whether these women would have this apparently strong bond with any other body part if it became endangered. Or is it mainly the fear of losing an organ that they strongly associate with their femininity?

## Between Stigmatization and Public Issue

Many illnesses and bodily changes are stigmatized by society. According to Erving Goffman (1975) [11], a stigmatization arises when something does not fit social norms, for instance, when a body is different from the socially accepted ideal. If a person's behavior or body deviates from the social ideal or norm, he or she is in danger of being discredited by third parties. Often the social acceptance for being different is absent, resulting in stigmatization, which can lead to exclusion and disaffirmation in social interactions and thus lead to a feeling of inferiority and/or the feeling of having a deformation.

As mentioned above, pretentious bodily ideals exist, especially for women. If after breast cancer the look of the female body changes due to a (partial) mastectomy or a surgery scar along her breast, this can be the case. Pitts (2005, 184) expresses it well:

“(...) women often feel a social duty to hide signs of illness, repress feelings of anger or grief, embrace an optimistic attitude and even focus on beautification techniques. Sociocultural fears and expectations about femininity, women's sexuality and illness encourage a sense of shame and discrediting about breast cancer, and work to 'isolate and silence' women about its horrible realities”.

In order to restrict or avoid the perception of stigma by others, persons frequently do not talk about their stigmata; they hide them, or make them invisible to counteract social exclusion, but also to avoid embarrassing others (Frank 1995) [12]. Goffman (1975) suggests that individual techniques are used to hide stigma. In the case of breast cancer, visible surgical scars due to the partial or complete removal of the breast(s) can be covered by clothing; the unevenness of the front upper body can be compensated for by wearing a prosthetic in the bra, or by breast reconstructions. However, a lymphedema of the arm as a result of breast surgery cannot be hidden, because it spreads down to the hand and fingers, and thus is visible for “outsiders.”

In western society nobody wants to see bodily defects, especially those related to femininity. For Broom the “breast cancer crisis has a lot to with lingerie,” (2001, 259) meaning the way it is hidden and how it has been commercialized by certain clothing. In fact, great pressure is exerted on women who have lost a breast to wear a prosthetic to publicly show the symmetry and thus a certain perfection of their bodies. This is severely criticized by the African-American writer and breast cancer victim, Audre Lorde, who mentions in her famous *Cancer Journals* that

thanks to the prosthesis, “Nobody will know the difference.” But she also underlines that by accepting the mask of wearing a prosthetic, one-breasted women reinforce their own isolation and invisibility from each other. In this manner they avoid stigmatization, instead of telling and showing other afflicted women that they are not alone (1997, 62). Thus the hiding of breast cancer is a kind of deception.

„When other one-breasted women hide behind masks of prosthesis or the dangerous fantasy of reconstructions, I find little support in the broader female environment for my rejection of what feels like a cosmetic sham. But I believe that a socially sanctioned prosthesis is merely another way of keeping breast cancer silent and these women separate from each other” (Lorde, 1997, 14) [13].

In some countries the stigmatization and social exclusion of breast cancer has diminished in recent decades, at least with regard to talking about it and giving women a voice when it comes to the medical treatment of the disease. This can be traced back to the women's movement in the 1960s and 1970s when a number of self-help groups, counselling and health centers and educational opportunities were organized by and for women. At this time, feminist-orientated health research was also initiated that began to explore illness and the suffering of women within a patriarchal society (Stahr 1998) [14]. Since then women have slowly gained a voice in their own affairs and can also decide on their treatment and surgical methods (Lerner, 2000) [10].

The transformation of breast cancer „from private expression (...) to public issue” as King (2000) [15] calls it can be seen in a new openness towards breast cancer. It has even become “trendy” to support breast cancer awareness (Edwards, 1994, 1) [16]. King (2000, 3) expresses this change clearly:

The first transformation involves the reconfiguration of breast cancer in the public discourse from a stigmatized disease and individual tragedy best dealt with privately and in isolation, to a neglected epidemic worthy of public debate and political organizing (...).

The United States exemplifies this trend; there, over the past two decades, the phenomenon of “going public” can be seen in many ways. One example are the so-called “Celebrity Survivors,” where more and more actors, politicians, and other famous women have become “ambassadors,” telling the public they have or had breast cancer. It started with actress Shirley Temple, singer Olivia Newton John and the former American First Ladies, Betty Ford and Nancy Reagan. Today Anastacia and Kylie Minogue and many other stars do likewise.

In the same vein, well-known models display their “new” bodies after a mastectomy in magazines. Probably the most famous example is the model Matuschka, who in 1991 was diagnosed with breast cancer and had a mastectomy. Following her surgery, which later she discovered had not been necessary, Matuschka became an activist for breast cancer issues. To increase awareness of the prevalence of breast cancer and also to suggest a more positive self-image for women who had had mastectomies, she began producing artistic portraits of herself, many of them revealing the results of her mastectomy. Through her photographs she tried to point to the bodily consequences of this illness. “I wanted to show that a woman can be beautiful, sexy, strong and powerful, no matter what her body looks like.” Her first famous picture appeared among other journals in 1993 in the *New York Times Magazine* and at that time was considered very controversial. While some breast cancer patients were outraged that Matuschka dared to show her scar in public, others were glad she did it. Some feminist health scholars call her the “pin-up-girl of breast cancer” because of her efforts to demonstrate a still beautiful body (Broom, 2001, 261) [17].

Other survivors chose a different way to display their scar as a symbol of their wounded and suffering body. For instance, British photographer Jo Spence portrayed herself in her photographs “Narratives of Disease” without a head. On her thorax the name “monster” can be read. Her intention was, using narratives, to start a critical discussion concerning the way in which disease and medical treatment can suppress a woman’s body. Another example is Deena Metzger, who is known for her “Warrior Poster” (1979). It presents her naked, raising her arms to the sky, showing she is enjoying life and fighting her illness; the caption reads, „I have the body of a warrior who does not kill or wound (in Lerner, 2001, 271) [18]. Broom argues because Metzger (and Audrey Lorde as well) call themselves “warriors,” “they link their illness to their political understanding of injustice, racism, violence and sexism.” Their fight is not so much against the „bodily invader,” but against discrimination of women in a capitalist society (2001, 261).

Another example of the way in which North Americans and those in other countries are publicly raising awareness of the fight against breast cancer is the pink ribbon. According to Margaret Welch, Director of the Color Association of the United States, pink is a color that is “playful” and “life-affirming,” and has a “calming effect” whilst also being “lessening of stress” and “health giving” (Fernandez, 1998, 54-55). In Goffman’s words (1975), the pink ribbon can be described as a “stigma symbol” which publicizes a stigma. Women’s organizations especially,

such as the cosmetic company Avon or the Susan G. Komen Breast Cancer Foundation, are among the distributors of this ribbon. Now this breast cancer symbol can be found on many products ranging from jewellery to yoghurt pots to ski poles, tennis-ball cans and licence plates. It seems that a certain kind of commercialization is connected with it. According to Maren Klawiter (1999) and Samantha King (2000; 2006), the pink ribbon is part of the breast cancer business. They both argue that cancer and especially breast cancer “sells.” Breast cancer is presented as “product and source of profits of a global cancer industry,” as Klawiter (1999, 106) writes.

Despite these negative associations with commercialization in recent years, the outsider perspective on breast cancer has generally become more open. This openness influences the possibility for breast cancer survivors to express and demonstrate feelings that deal with their individual illness more overtly. An example can be noticed in fine art. Survivors not only use their artwork for therapeutic reasons, but also publicly express inner feelings related to breast cancer. The same is mirrored in the field of publications. Breast cancer is no longer limited to medical literature. Besides, the humanities are now taking up this disease in their research, and individual women write about their personal experiences with treatment and coping, expressed in autobiographies, poetry and prose. Here especially the internet has opened new possibilities and networks.

In Germany, breast cancer is only slowly losing its taboo. The first non-medical publications have begun to appear on the book market, and American concepts such as the pink ribbon and the Komen Race for the Cure are trying to take hold. But their success is minor compared to that in other countries. The pink ribbon is solely familiar to insiders, and Komen only by the people living in the Frankfurt area where it is located. Despite a rising openness towards discussing breast cancer certain restrictions remain: in Germany and other societies visible one-breastedness or non-breastedness is still considered socially taboo. It is acceptable to talk about breast cancer, but the actual loss of a breast, associated by many – male and female – with a loss of femininity, still has to be hidden from public view, no matter in which country. Women’s views about breast cancer – the insider perspective – are discussed in the second part of the paper.

## **The Insider Perspective: The “Bodyness” of Breast Cancer Survivors**

A qualitative research design in the form of in-depth interviews was used to give women a voice and present their indi-



vidual, lived experiences with their “scared” or “wounded” body. The interviews were conducted in the homes of the patients, so as to provide a familiar environment for them. To present the women as individuals their names were replaced by pseudonyms rather than numbers or letters. This study was very personal and provides insight into the emotions and private sphere of 18 physically active women all of whom had breast cancer. After their surgery, breast cancer patients are confronted with a lot of problems. First of all, there is the fear of death. Then they have to cope with the effects of a punishing and intense therapy regime, especially when they have had chemotherapy. Furthermore, partnership and sexuality are not easy to deal with. I deliberately talked to those survivors whose illness had appeared some time ago, who might have become familiar with their changed body and life. Thus, the women interviewed had lived for some time with their changed bodies and were able to develop a relationship to it and set up a new life.

Arguably a novel aspect of my analysis relates to its focus on the “private body in public space.” This aspect is connected with physical activity and nakedness. In Germany it is not unusual to take a shower after exercising in one’s sports club. The shower areas and the changing rooms are often open spaces where the naked body becomes visible to other users as well, just as in public saunas. In Germany, one is not allowed to wear any clothes in these saunas which are often used by both men and women at the same time. How do women who have had breast surgery confront these situations in which their scar, usually hidden, suddenly becomes visible? A further example of a venue where men and women often shower together for practical reasons is camping sites in Europe; nor is topless sunbathing unusual at European beaches and outdoor pools. Another aspect of the wounded body and the public space is chemotherapy-induced hair loss. Exposing a bare head publicly makes it obvious that a woman has cancer. How do these women approach the public? Usually such body signs make their cancer immediately obvious. These two aspects are the main focus in the following, which I define as the “wounded body in public space”.

Having referred to some socially constructed aspects that make up the outsider perspective of breast cancer, this part of the paper allows breast cancer patients a voice to expose their inner feelings about their changed bodies. In the case of breast cancer, life-saving surgery can mean a partial or complete removal of the afflicted breast, which can change a woman’s relation towards her body completely. This often results in a changed body image and self-concept. Thus my research considered such aspects as physical appearance, body contacts, hygiene and phys-

ical performance and activities. I focus here in particular on the operation scar, dealing with chemotherapy, and the private, wounded, body in public space. Finally I briefly reflect on the process of getting the women talking about their breast cancer.

## The surgery scar: A symbol of pain and loss

The surgical scar takes on great significance for breast cancer survivors’ relation towards their bodies. It reminds them continually for the rest of their lives not only of their disease, but also of the complete or partial loss of their breast(s), a body part which has special meaning not only for women but for society as well. Thus the scar becomes a continual symbol of physical and emotional pain as well as of the missing breast. Quite a few interview partners spoke of their inner feelings when sitting in front of a mirror looking at their scar, like Mrs. Müller:

I have spent so much time in front of the mirror, unbelievable amounts of time. Well, to understand it somehow, that it’s like it is now and how it is, and – and – I don’t know what else I did in front of the mirror. But I had a lot of time to look at it. And to look from the side and from the front, and now it is a bit better (laughs) – and a lot of time, well to, to realize at all that this is me, yes.

A body is always public and visible. Still certain parts and changes can be hidden from an outsider’s view. In coping with breast cancer, breast prostheses and breast reconstructions can help to conceal associated bodily “defects.” Because they hide a social stigma, they can also play a role in recovering mental balance, in gaining a more positive body image, and in facilitating integration in everyday life; however, they do not have the power to heal the physical body. The reaction of my interview partners to such reconstruction generally was rather negative. Only two had decided to have a breast reconstruction, and they chose it in the hope it would be easier for them to continue their exercising.

Mrs. Müller, who originally was not in favor of such a surgery, decided to have it because she could continue her sports activities and continue to wear her clothes:

(...) Well, and I had decided because of sport, well, I first wanted to have my own body material (back muscle). And then shortly before the surgery I withdrew from it (...). I was concerned because, because of cross country skiing (...), because I thought I run and I thought it is more simple if I have something there and with my old bras and everything, everything stays the way it is and I do not have to buy any special things and then maybe something will fall out or the like. I thought about it for a

long time. My first thought was, never will I have a reconstruction. (...) that is somehow, (very low voice), one has to be very self-conscious, when a breast is amputated (...) and I thought always about my tight things (laughs) and I wanted to have it that way, that it is not visible.

All other women interviewed were using prostheses which can be put into a bra so that their missing breasts will not be noticed. Especially the first months and years after the surgery the women had the tendency to wear the prostheses every time they left their home. But in some cases this has changed over the years. Besides the prosthesis, clothing is closely connected with hiding the lost breast and the scar as well. According to Goffman, clothes can hide a stigma and make it invisible.

## Chemotherapy

Not every sign of breast cancer can be hidden. Chemotherapy that results in a loss of hair or a lymphedema are traces that make cancer visible. Seven of the interviewed women were treated with chemotherapy and suffered from hair loss. How did these women present themselves in public? Did they hide their baldness through caps, wigs or bandanas? Did they withdraw to their homes and avoid the public?

The interviews showed that the hair loss was a serious psychological burden. Often the women recalled that before the surgery they were more afraid of chemotherapy than of the actual surgery. All of them very clearly remembered when they lost their hair.

Mrs. Schmidt: I was very distressed by it, I have to say. Well my memories are always certain pictures, and I am sitting in front of this mirror with my upper body uncovered and my husband behind me. He is shaving the rest away, and I cry and cry and cry. Well, it did matter a lot to me. And even though I knew and was told that everything would come back and so, this situation was shocking.

Bettina noticed during some work in her garden that she was losing her hair all of a sudden. Her husband immediately shaved her head completely and then they opened a bottle of champagne:

It was horrible. It was really horrible, (...) I was in the garden and all of a sudden my hair was flying through the air. I grabbed my hair and I had a whole bundle in my hand (...) and then the first thing I did was cry. Well, one needs to get used to pulling out one's own hair (laughing). And then he [husband] said, you know, we won't dramatize it, I will go and get

a friend's scissors and then I will crop your head (...). Then we sat together in the bathroom, opened a bottle of champagne and even laughed. (laughs). Well, then it was ok (...), one just looks different. And one has to learn to accept how one looks. Some people look good bald, I don't.

Carol lost her hair two weeks after she started chemo. It was during a short trip that she decided to go to the hairdresser and had her hair cut. She even was joking when she told the whole situation to her family. Actually in the beginning they all made fun of it together when they saw her bald.

I decided I needed go and have my head shaved, because, my hair was down to here, and it was just everywhere. (...) I brought my wig along, knowing that this was gonna happen, and this guy comes over to me and says this hairdresser, he says, (...) "I know exactly how to style wigs." So he put my wig on, and he was styling my wig (...) And, so we come home, I walk in the door, and my hair looks pretty much the same as before I had left. And I go, "Guys," to my kids, five and seven, "I got a surprise for you," and I take my hair, and my wig and I throw it off. And they laughed, they laughed for like ten minutes, and then when I turned around, they said, "Mum, what's for dinner?" (laughing)

These statements show that, on the one hand, losing their hair represents a tremendous psychological burden to these women; on the other hand, they had enough energy to make fun of the situation, a situation they shared with their partners.

After the first loss the women had to decide what to do with their bald heads. In the beginning, they all decided to hide them. They tried various possibilities; some chose striking wigs or used conspicuous make-up and jewellery, or even changed their dressing style. Mrs. Müller is a woman who experimented with her bald head. She chose different ways to deal with it for different public spaces. In the beginning she wore a wig, especially when she left home and when she went to the rural area where her mother lives and everyone knows everyone else. Later on, the wigs grew bothersome:

Again sport helped me. I cannot run and wear a wig or swim and wear a wig. Well, it was summer, and then I took off those wigs and the headscarves as well. They did not look good on me. I thought being bald-headed is better for me, and I started to use big earrings and conspicuous make-up. I always used make-up and that was for me a good thing. It was completely new to me. Before I had always covered my face with my hair. Now I thought it is really exciting. And I did manage it, and often

people asked me whether I did this because of fashion. I always answered that I am past the age of doing it for reasons of fashion. But I had great experiences, and often people talked to me, also in the rehabilitation hospital.

Later in the interview, Mrs. Müller added that she went around bald in public, even in front of her school class, when she began teaching again.

A bit similiar to Mrs. Müller, Bettina also changed how she appeared in public. She not only changed her clothes but also bought the craziest types of wigs, in different styles and colors. And she criticizes the companies that produce wigs and fashion for breast cancer patients, as being only for older women and not at all fashionable:

(...) Then I bought ten wigs on the Internet, a big variety, crazy ones, red and very long hair, Rasta curls. Every week I had a different hair style. (laughs). Everyone looked at me and thought, "What does she look like?" but I did not care. I thought everyone sees it anyway, (...) even with these expensive wigs that look so cheap. And that is the bad thing. There are so many young women and this whole service branch has not changed yet. You notice it when you go to these wig studios, you can only get the one with short hair, you look like a grandma (laughs). The same with bras, only for 60-,70-year-olds, just because you are missing a breast.

## The Private Body in Public Space

As previously mentioned, this study was conducted with physically active women who exercised a few times a week. A quote by Mrs. Müller gives an impression of how important physical activities were for the interview partners – in some cases also during the treatment. Mrs. Müller mentioned that she jogged and swam during chemotherapy. This made her proud. Especially at the beginning of her treatment she crossed a lake against her friends' advice.

I always did during chemo – I had more time then, well, I didn't have to go to work, and I did run and swim during chemo. Somehow I was proud of it (...). And I did, well, maybe three, four kilometers, not more. But on a regular basis and short – well; I'm not sure, but Tuesdays I had chemo and Fridays I went running again. And, and I can remember, (...) I thought that is great, you can do this, that after the fifth or the sixth – I had six chemos – I stopped running. I became weaker every day, I didn't do much after the sixth one. But once I swam across the lake,

all by myself! Everyone said it would be better not to, but I felt safe, and swimming was great. And yes, and I thought, too, that it would help me, I also had read that (laughs). And I felt it, too.

In Germany, physical activity is very often associated with situations in which one has to reveal one's "private body" (changing rooms, showers, saunas, swimming, or nude beaches). Many breast cancer patients also thought about how others might react when noticing that one breast is missing or see their scars or lymphedema. Consequently it was not easy for them when – prepared or unprepared – they found themselves in situations in which they reveal to others their operated body. This was especially the case when they visited a sauna, went to nudist beaches, swam naked, sunbathed topless, or took group showers after their exercise classes. These activities were all part of the lives of some of the patients before their illness.

Mrs. Kluge told of an experience with her running partners – all healthy women:

Yes, and then they said, we will go swimming afterwards, we will swim naked. When the first one told me that on the phone, mmm, "Yes," I said, "Well, Ok, I will join you." This was my first reaction. Then I thought, well maybe I should ask them what they think about it. Whether I should wear the prosthesis and a swimming suit or what. Then I thought, no, I won't do that. I look the same as they do naked. And then one said, "That's a very funny and easy one, this looks great and the breast has not been cut off completely. There is still a little mound, that was done well cosmetically." Yes, that was it; afterwards we went swimming (...).

So Mrs. Kluge thought beforehand about how to deal with the situation. For her running partners the sight of her operated-on breast wasn't as shocking as expected, rather the contrary – they dealt with it very positively and in a relaxed manner. They looked at the scar with interest, commented on it accordingly and then the topic seemed to be dismissed.

For Mrs. Müller, who in the meantime has no problems swimming naked or staying at a nudist beach, it was a long process from the first attempt after her operation – at that time still in her bathing suit:

No, I will do it in any case. Yes, I have done it for many years (...), well, it is a lake with a nudist beach. It is very nice, and such a thing I won't give up! Well, maybe I was a bit too meek, because then I thought, well, I do not want to attract attention.



Well, still, even with the implantation one sees it, but after 10 days I went to the lake in my bathing suit. It was hanging, but I still did it (in a low voice). (...). It was clear I would do it, even without the implantation. This was my aim, I was prepared. But still it was not easy, but my husband supported me totally.

Mrs. Müller emphasizes explicitly that she didn't want to give up naked bathing and that she refused to be restricted by the sickness and by what was visible. In the beginning, she still tried to conceal the scar by covering it with a towel. But since the scar also changed and she got used to it, she did not do it anymore. An interview partner who occasionally swam in a nudist area before her sickness wore a bathing suit during her first stay after the operation. However, as she noticed a single-breasted woman there, who was sunbathing in the nude, she felt great relief. Firstly, it was a confirmation that other women have the same problem as her and secondly it showed her that there were others affected who were able to stand by their sickness publicly, so that they need not be ashamed of walking around naked on a nudist beach.

I was with friends at the (...) nudist areas. And there I went for the first time again into the water. And I had a bathing suit on with prosthesis. And when I came out of the water there was a woman who had breast surgery lying in the sun, so naturally. It was so liberating to me that I was not the only one. There was a little barrier, there was one, and I'd say, this was the first time, I thought it was great.

That the public showing of the divested bust is treated differently in a group of affected or unaffected women than in a mixed group – including men – was noted by Mrs. Heinzmann. She said that on the one hand there were many things that she continued doing after her sickness, but going to a mixed sauna was not one of them. Furthermore, she now avoided mixed showers when camping. But there are also women who completely refuse to present their scar openly in public. This has no relation to age. 43-year-old Bettina, the youngest interview partner, for example, rejects lying on the beach single breasted or visiting the sauna, even if it is being used only by women, because she is not that “self-confident” and “would not feel good”, as she said.

Mrs. Bauer brought up another aspect. She observed that especially healthy women avoid the sight of the operated body. She noticed this in her water exercise class, which was for breast cancer patients but also attended by a few healthy women. The latter preferred to choose the few single changing rooms, whereas the breast cancer survivors predominately changed in

the communal cubicle. The healthy women also often waited before showering and stayed longer in the pool to avoid seeing the others naked – something which is normal in Germany when taking showers after exercise classes or swimming.

## Language barriers: The problem of speechlessness

Language is a medium through which the body and body parts can be pointed out in a symbolic way. The breast, for instance, has found entrance as a metaphor and idiom into our everyday language, but quite frequently it can also be found in lyrics (Hofmann 2004) [20]. Diseases, too, have gone through this “metaphorization,” as Susan Sontag describes extensively in her book, *Illness as Metaphor* (1978) [21]. Referring to cancer in general, she states that talking about it is frequently a taboo to avoid social stigmatization. Breast cancer is a special case. Although, as elaborated above, its public perception has changed during the last years, it still is not easy for all women to talk about this disease and their changed body [22-26].

German sociologist Anke Abraham argues that the body is a very delicate topic, especially when talking about intimacy and sexuality. In this case language patterns to express these concepts are often missing; Abraham calls this the “problem of speechlessness” (2002: 34). This could be seen partly in my interviews when the loss of the breast - a sexualized body part – was discussed. It led to the recall of deviant events and heightened emotions. Although most women interviewed had no problems talking about themselves and their disease, many avoided using certain words, among them “cancer,” “scar,” “prosthesis” and in some cases, “breast.” Frequently the women replaced these words by “this,” “these things” or, when they talked about cancer, they called the disease “it.” One woman even whispered when using the term “cancer.” Another survivor admitted that when she first had cancer, she was unable to use “this word”; she “was blocked,” as she described it, but now, after two years, it was no longer a problem for her. Although the women interviewed were only able to voice “cancer” or “breast cancer” hesitantly when referring to themselves, they had no problem using these words when they talked about other women's breast cancer. This speechlessness might symbolize for my interview partners a certain distance from their bodies and their disease [27-34].

## Conclusion

As I have suggested, the female breast plays a special role as a socially accepted symbol of femininity, fertility, eroticism and sexuality in western body history and culture. Through

its biological, but also artistic, literary, religious, political and commercial discourse, society puts a great deal of pressure on this body part, more so than on any other organ. Thus it is not surprising at all that once patriarchal society's picture of the "ideal" breast is destroyed or distorted through breast cancer, society has problems in coping with it. It is not only life, but femininity that is threatened, in the eyes of both the public and the afflicted woman. Through the pressure of society this disease of the "Other" in Simone de Beauvoir's sense becomes a collective fear. This is also reflected in Kaspar's words (1994, 265):

A breast cancer crisis is just such a life event – the competing public and private meanings associated with breast cancer are often dramatically, painfully revealed. More precisely, women diagnosed with breast cancer often discover that the social assumptions which define them as women no longer match their own interior definition of what it means to be a woman.

As shown, the outsider perspective of breast cancer has changed over the years: public pressure to hide the illness has diminished to some extent and today women can talk about their breast cancer much more openly than a few years ago, at least in some countries. But, as Pitts (2005: 484) notes, women's breast cancer experience has been "shaped by beauty norms and consumerism." And it is still a problem for many afflicted woman to show the scar of a breast cancer surgery, a scar that society does not want to see because it is not in accordance with their picture of the 'ideal woman.' This can be a real restriction for those women who want to continue their habits of showing the private body at certain places such as beaches or saunas and live the way they lived before their surgery.

The insider perspective on illness can never be over-generalized; it is always highly subjective. Nonetheless it can be noticed that the women interviewed in this study were very open. They talked about their illness, their life changes, their new bodies and the emotions connected to their cancer. With regard to their appearance in public, many of the interview partners tried to continue their habits. Despite social pressure they do not mind revealing parts of their private body or naked body in public, be it with a wig or bald-headed, although breaching social restrictions has not been an easy step for any of them. Due to this openness, to some extent, I may have obtained a one-sided view. I have not reached those women who are hiding their breast cancer and who avoid talking about it, nor how they experience their illness, their changed body? Investigating why they do not they talk about it, may reveal that public pressure against discussing this taboo subject is still much stronger than assumed? Even so

speechlessness amongst my group of interviewees could sometimes be noticed when the interview partners talked about their lived body and especially about their breast. It shows that these women will never forget that they have had a life threatening illness, and a "scarred body" which has been wounded in many ways, as expressed by one interview partner:

And it – it always helps if you treat this somewhat – well, I don't want to say deformed – well, this damaged body – confidently, because it's – how should we say – wounded.

In this respect they will stay "eternally wounded women" as well as "wounded storytellers," to borrow the titles of books by Vertinsky (1989) and Frank (1995) respectively.

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