

From the Outsider to the Insider Perspective: Bodyness and Physical Activity in the Lives of Breast Cancer Survivors and Female Heart Patients

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Abstract

Long-term illnesses have a major influence on how a person experience his or her body and can totally change a person's relationship with it. This paper focuses on German women with breast cancer and coronary disease. These two chronic illnesses are the leading causes of mortality in German women and women in order Western societies. Based on a qualitative study in form of in-depth interviews done with 18 physical active breast cancer and 8 cardiac patients these women are given are voice to talk about their lived body. Here mainly the role that their changed body, physical activity and sports play in their lives in explored. The questions focus on how these women experience and treat their 'new' bodies. What role does physical activity and sport play in the phases of their illness, recovery and reintegration into everyday life? Does physical activity support a positive quality of life and sense of well-being? The interviews show how these women developed a bond with exercise and sports and which social and personal barriers they had to overcome. A special focus will be put on how society constructs both illnesses and as such influences how the patients feel about their body and deal with it in public.

Keywords: body, illness, physical activity, women

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Introduction

This article focuses on women with a life threatening chronic disease: breast cancer and coronary diseases, the leading causes of mortality for women in western societies as the following figures show. Every year about 53% of the deaths in German women are due to cardio-vascular diseases (about 244,000 women and 171,000 men). In the United States it is about 320,000 women. In contrast to these numbers, in 2000 18,000 German women died of carcinoma of the breast, which is the foremost cause of cancerous death in German and American women. Alone in Germany there are about 57,000 new cases each year; around 40 percent of them are under the age of 60. Every 9th woman is afflicted with this disease. In the United States, every 7th to 8th woman is affected¹.

Long-term or chronic illnesses have a major influence on how a person experiences his or her body and can totally change a person's relationship with it. Such illnesses often result in a person's alienation from his or her body which seems to become 'other' to itself. But 'otherness' is constructed differently according to what part of the body is ill, which organ is afflicted, and how this organ is perceived in society. Thus illness connected with different bodily organs can be understood as partially constructed by socio-cultural relationships.

However, the body is not only a cultural sign; it is a *perceiving subject* as well. In the German language there is a distinction made between the words 'Körper' and 'Leib'. The former term refers to the physical body, to the human organism. The latter refers to the lived body, to what might be called the 'embodied soul'. The French phenomenologist Merleau-Ponty wrote that this lived body is marked through its ability to perceive; thus, it is through the *Leib* that an

¹ Elisabeth von der Lohe, *Koronare Herzkrankheiten bei Frauen. Prävention, Diagnostik, Therapie* (Berlin and Heidelberg: Springer Verlag, 2002), 3; Anne S. Kasper, "The Social Construction of Breast Loss and Reconstruction", *Women's Health: Research on Gender, Behavior and Policy*, 3 (1995): 197; Gudrun Kemper and Ulla Ohlmes, eds. *Jede Neunte...Frauen berichten von ihren Erfahrungen mit Brustkrebs* (Berlin: Orlanda Verlag 2003), 9-10.

individual gets to know the physical world around him/her. When experiencing our body (*Leib-Erleben*), we are aware of a disharmony; we experience physical dysfunctions: tiredness, fatigue, pain, disease, injury or disability². Disease or illness disturbs the duality of body and mind. Illness and other dysfunctions destroy the harmony between our physical, social, and moral selves, leaving us searching for its reconstitution³.

The 'lived body' is related to a person's insider perspective, his or her inner feelings and emotions. Relating to illness, Peter Conrad, a medical sociologist, emphasizes the importance of the insider perspective:

'(...) 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 the illness experience in a more inductive manner. The conceptual or theoretical issues are not always a primary concern'⁴.

For Iris Young a lived body is not free from culture, it is 'enculturated' by various influences, such as habits.

'Contexts of discourse and interaction position persons in systems of evaluations and expectations which often implicate their embodied being; the person experiences herself as looked at in certain ways, described in her physical being in certain ways, she experiences the bodily reactions of others to her, and she reacts to them'⁵.

In this article I want to draw attention to the insider perspective of

² Ommo Grupe, "Leib/Körper", in Grupe, O./Mieth, D. eds. : *Lexikon der Ethik im Sport* (326-330). (Schorndorf: Hofmann, 1998), 329.

³ Jean Comaroff, "Medicine: Symbol and Ideology", in Peter Wright and Andrew Treacher, eds. *The Problem of Medical Knowledge. Examining the Social Construction of Medicine* (Edinburgh Edinburgh: University Press, 1982), 51f.

⁴ Conrad Peter, "Qualitative Research on Chronic Illness: A Commentary on Method and Conceptual Development". In *Social Science and Medicine* 30(1990) 11, 1259.

⁵ Iris Marion Young, *On Female Body Experience. "Throw like a Girl" and other Essays*. (Oxford: University Press, 2005), 17.

physically active women with a long-term illness as my main focus. In the first part, however I will examine some arguments about the socially constructed nature of illness, to shed light on the ‘outsider perspective’ of women with breast cancer and coronary disease, which Conrad describes as

‘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.’

To understand how western society constructs breast cancer and female heart disease a special focus is put on the organs breast and heart. This culturally shaped outsider perspective centers upon how the physical body influences how patients feel about their individual illness, their body and how they deal with it in public. Erving Goffman’s classic work, *Stigma*, is especially useful for understanding the social construction of illness. The second part of the article, using a qualitative study based on in-depth interviews conducted with physically active breast cancer and cardiac patients, explores the role the body, physical activity and sports play in their lives. Thus afflicted women are given a voice and their insider perspective is revealed to gain insight into the lived body.

Visibility and Invisibility of Organs: Between the Pink Ribbon and the Red Dress

Body parts and organs play a significant role in social discourse and power struggles, especially when they relate to a woman’s body. According to a Gallup study, breast cancer is the most feared disease among women, although many more women die of heart disease⁶. 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

⁶ Elisabeth von der Lohe, *Koronare Herzkrankheiten bei Frauen. Prävention, Diagnostik. Therapie* (Berlin/Heidelberg: Springer-Verlag, 2002), 6.

attention than any other organ and none other has been exploited to such an extent in the western world. Because of its great potential for expression the breast has become a symbol of femininity, fertility, and sexuality. At a very early time in their lives, girls learn – or, rather, society makes them learn – that their breasts have something to do with their sexual identity. The German physician Ingrid Olbricht describes it as an ‘organ of relationship’ which communicates⁷.

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 breasts⁸. The breasts underlie a strong cultural influence and carry a ‘cultural weight’ although they are part of the intimate sphere of a woman, as Latteier writes. She goes further; in relation to the Western world she speaks of a ‘cultural breast obsession’⁹, an argument that is supported by Marilyn Yalom, author of *A History of the Breast* (1997), who summarizes the functions of the breast:

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 imagination¹⁰.

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

⁷ Ingrid Olbricht, *Die Brust. Organ und Symbol weiblicher Identität* (Hamburg: Rowohlt, 1989), 102.

⁸ Young, “Breasted Experience”, 125; Ann Tait and Mavis Wing, “Körperbild und teilweiser oder vollständiger Verlust der Brust”, in *Körperbild und Körperbildstörungen*, eds. Mave Salter Wiesbaden: Ullstein, 1999), 137.

⁹ Carolyn Latteier, *Breasts: The Women’s Perspective on an American Obsession* (New York/London: Harrington Park Press, 1998) 111, 165.

¹⁰ Marilyn Yalom, *A History of the Breast*. (New York: Ballantine Books, 1997), 183.

accordance with the norms set by themselves or by society, many women find their physical aesthetic and body image threatened, which is also seen in the great number of breast reconstructions.

Similar to the breast, the heart is also an organ with great symbolic value; moreover it is considered the center of feelings in western societies. In European history it was very often referred to as the organ in which the soul lives. 'Heart means the reality of the whole person, it means a unity of body and soul in its original sense.' The heart stands for the center of the human being¹¹.

Merleau-Ponty pointed out that 'one's own body is in the world as the heart is in the organism'¹². In contrast to the breast, without the heart, life functions could not be supported. Each person is born, independent of gender, with a heart. Because of its vital importance the heart lies centrally and hidden in the protective thorax – deep inside the human, imprisoned in the body (*Leibgefängnis*)¹³. Unless it is being operated on, the heart is not touchable nor is it outwardly visible; thus, unlike the female breast, it does not have a visible potential of expression, despite the fact that it responds more rapidly than most organs to emotions, with the quickening or slowing of the heartbeat. However, its ability to pump regularly shows a certain dynamic and consistent motion; its strength can be felt through the rhythm of the heartbeat or pulse – sometimes one can even hear it.

The importance of the heart for western society is reflected in the fact that iconic representations of the heart with its double-shouldered symmetrical form and pointed base have become an ever-present symbol in our western culture. One encounters painted, shaped, embroidered

¹¹ Susanne Hahn, ed., *Herz. Das menschliche Herz. Der herzliche Mensch. Begleitbuch zur Ausstellung "Herz" vom 5. Oktober 1995 bis 31. März 1996 im Deutschen Hygiene -Museum Dresden* (Dresden and Basel: Verlag der Kunst, 1995), ix.

¹² Maurice Merleau-Ponty, *Phänomenologie der Wahrnehmung*. (Berlin: Walter de Gruyter & Co. 1966), 239.

¹³ Claudia Benthien, *Haut. Literaturgeschichte-Körperbilder-Grenzdiskurse* (Reinbek: Rowohlt, 2001), 43.

images of hearts which express affection towards another person, living being or even material things daily. To underline this affection it often appears in red, the color of love and passion.

Nagler differentiates between a ‘cardiological’ and a ‘cordiological’ heart:

“The *cardiological* heart pumps, fails, depolarizes and repolarizes, fibrillates, is palpated, auscultated, electrocardiographed, catheterized, biopsied, digitalized, computer tomographed, fibrinolysed, compensated and transplanted.

The *cordiological* heart sings, laughs, rejoices, cries, awakes, flourishes, complains, trembles, shatters, bleeds, languishes, breaks (...),¹⁴.

Between Stigmatization and Public Issue

The symbolism of the body and body parts is important in the ways we construct our understanding of illness. Many illnesses and bodily changes are stigmatized by society. According to Erving Goffman, stigmatization arises when something does not apply to social norms, for instance, when a body is different from the socially accepted ideal. Often the social acceptance for being different is absent, resulting in stigmatization, which can result in exclusion and disaffirmation in social interactions and thus lead to a feeling of inferiority and/or the feeling of having a deformation. To restrict or avoid the perception of a stigma by others, persons frequently do not talk about their stigma; they hide it, or make it invisible to counteract social exclusion, but also to avoid embarrassing others¹⁵. Breast cancer is an example where the look of the female body changes due to a (partial) mastectomy or a surgery scar along the breast; this can result in the hiding of the scars. Pitts expresses it

¹⁴ From Frank Nagler “The Mythology of the Heart”, in Gail Godwin, *Heart: A Personal Journey Through Its Myths and Meanings*. (New York: Harper Collins ,2001), 142.

¹⁵ Arthur Frank, *The Wounded Storyteller. Body, Illness, and Ethics*. (Chicago and London: The University of Chicago Press, 1995), 31.

perfectly:

‘(...) 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’¹⁶.

Goffman mentions that individual techniques are used to hide a stigma¹⁷. In the case of heart disease and breast cancer, visible surgical scars can be covered by clothing; the unevenness of the front upper body due to the partial or complete removal of the breast(s) can be compensated for by wearing a prosthetic in the bra, or by breast reconstructions. However, a lymphedema, the swelling 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 to ‘outsiders.’

In western society nobody wants to see bodily defects, especially those related to femininity. With respect to covering the loss of a breast, society goes so far as to exert pressure on women who have lost a breast to wear a prosthetic to publicly show 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 through 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 alone¹⁸; thus the hiding of breast cancer can be seen as a kind of deception.

¹⁶ Victoria Pitts, “Illness and Internet Empowerment: Writing and Reading Breast Cancer in Cyberspace,” in Conrad, P. (ed.) *The Sociology of Health and Illness: Critical Perspectives* (481-499). (New York: Worth Publishers, 2005), 184.

¹⁷ Erving Goffman, *Stigma. Über Techniken der Bewältigung beschädigter Identität* (Frankfurt: Suhrkamp Verlag, 1975), 18.

¹⁸ Audre Lorde, *The Cancer Journals. Special Edition* (San Francisco: aunt lute

In some countries the stigmatization and social exclusion of breast cancer have diminished in the last decades; this has resulted in a transformation of breast cancer 'from private expression (...) to public issue.' It even is 'trendy' to support breast cancer awareness¹⁹. King expresses this change more 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 (...)²⁰.

Another example of how Americans and now many other countries as well publicly raise awareness for the fight against breast cancer is the pink ribbon²¹. In Goffman's words²², the pink ribbon can be described as a 'stigma symbol' which publicizes a stigma. Meanwhile this breast cancer symbol can be found on many products ranging from jewellery and yoghurt pots to ski poles, tennis-ball cans and licence plates. It seems that a degree 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

books, 1997), 62.

¹⁹ Jane Edwards, "Private cancer, public cancer: Guilt and innocence in popular literature," *Australian Journal of Communication* 21 (1994) 2: 1.

²⁰ Samantha King, *Civic Fitness: The Politics of Breast Cancer and the Problem of Marketing Generosity*. (Ph. D. diss., University of Illinois at Urbana-Champaign, 2000) 3. Her dissertation was published as a book with some changes: Samantha King, *Pink Ribbons, Inc. Breast Cancer and the Politics of Philanthropy*. (Minneapolis and London: University of Minnesota Press, 2006).

²¹ The inventors were Evelyn H. Lauder, founder and president of the Breast Cancer Research Foundation, and Alexandra Penney, then editor of *Self* Magazine. See <http://www.pinkribbon.com>.

²² Goffman *Stigma*, 117; 127.

source of profits of a global cancer industry', as Klawiter writes²³.

But, it seems, this new openness in certain areas does not extend to showing one-breastedness or non-breastedness in public. This is still considered a social 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.

'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 socially sanctioned prosthesis is merely another way of keeping women with breast cancer silent and separate from each other'²⁴.

The public perception of heart disease is completely different from breast cancer. One reason that has already been mentioned is that it is usually invisible and can be associated with both men and women. Public attention is more on a medical level. The fact that women can have a heart attack is not very well known by the public. For example an Emnid Survey (2004) showed that of 531 German women asked only 28 percent knew that women could die of a heart attack just as often as men. The majority thought it was the major cause of death for men, but not for women²⁵. Medical science can be blamed for this ignorance to some extent. Until a few years ago all major surveys were done with men; women were excluded from the big studies or underrepresented. This has changed in recent years (Maschewsky-Schneider 1997, 15). 'The big cardiological studies of the last decades presented women as beings with no hearts', as Moreano wrote (1995, 70). Today women are still often treated differently when having the same symptoms as men. Frequently

²³ Maren Klawiter, "Racing for the Cure, Walking Women, and Toxic Touring: Mapping Cultures of Action within the Bay Area Terrain of Breast Cancer," *Social Problems* 46 (1999) 1, 106.

²⁴ Lorde, *The Cancer Journals. Special Edition*, 14.

²⁵ www.frauenherz.info/emnid-umfrage.asp.

their complaints are considered to be psychosomatic, and often physicians misinterpret women's heart attack symptoms, which are different from men's (Helferich 1996, 113; STZ 18.12.2004, 10; Lorber/Moore 2002, 139)²⁶.

Juanne Clarke compared articles on cancer and heart disease in selected magazines and journals²⁷. She found that the media portrayed cancer as "mutilation, excruciating and disgusting suffering, and finally death. To some extent, persons with some cancers are held blameworthy because the cancers could have been prevented through early medical checkups. She concluded that the media make us believe that 'it is the individual who is ultimately culpable.' Heart disease is portrayed in a far more optimistic way. It does not affect the whole person or the moral being of the person. 'Heart disease is an outsider that can be repelled through quick decisive action' and medical care²⁸.

Whereas 'Women's experience of breast cancer has also been shaped by beauty norms and consumerism' (Pitts 2004, 484), the commercialization of female heart disease is just starting. Now some organizations are trying to 'go public' with initiatives. The first companies seem to have found a market and are attempting to start a kind of commercialization similar to that done with the *pink ribbon*. It is not a *red ribbon*, which is connected to AIDS, but a *red dress* that was created to support awareness about women with heart disease. The campaign 'Go Red for Women' that the American Heart Association started with the support of the department store chain MACY's was the first initiative for it. 'The color red and the red dress have become linked with the ability all women have to improve their health and live stronger, longer lives²⁹'. In 2008 for the first time, the American Heart Association named February

²⁶ This study is an exception. Since 1948 when the study was initiated in the American city of Framingham, Massachusetts, women were integrated (www.framingham.com/heart/background/html).

²⁷ Clarke also discusses AIDS, which is omitted here.

²⁸ Juanne Clarke, "Cancer, Heart Disease, and AIDS: What do the media tell us about these diseases?" *Health Communication*, 8 (1992), 115-117.

²⁹ Pamphlet of the American Heart Association "Go Red for Women", 1.

1st the 'National Wear Red Day'. Breast cancer support associations, on the other hand, have dedicated October as a special awareness month for breast cancer for over 25 years.

Having discussed some aspects of the 'outsider perspective', in the second part of the article I place the 'insider perspective' of breast cancer and female heart disease patients at the center of focus in order to better to reveal aspects of their 'lived body'.

The Insider Perspective: The 'Bodyness' of Breast Cancer Survivors and Female Heart Patients

This research study was very personal and offers insight into the emotions and private sphere of 26 physically active women who either had breast cancer or suffered from heart disease. A qualitative research design in the form of in-depth interviews was used in order to give the women a voice and present their individual lived experiences with their 'scared' or 'wounded' body. The interviews were conducted in the homes of the patients to provide a familiar environment for them. For the study their names were replaced by pseudonyms to present them as individuals and not just as letters or numbers³⁰. After their surgery both breast cancer and heart patients were confronted with a lot of problems. First of all there was the fear of death. Then they have to cope with the effects of punishing and intensive therapy, especially when they have had chemotherapy. Later they have to decide about special rehabilitation programs. I wanted to talk to survivors who had become familiar with and used to their changed body and life. Thus, each of the women interviewed had lived some time with their changed body and had been able to develop a relationship to it and had set up a new life³¹.

³⁰ For more arguments about the qualitative study of breast cancer patients, see Ann S. Kaspar, 'A Feminist, Qualitative Methodology: A Study of Women with Breast Cancer,' *Qualitative Sociology* 17 (1994).

³¹ I want to mention here that in the case of the interviews with women who had had breast cancer I was sometimes confronted in the interviews with a phenomenon that the German sociologist Anke Abraham has called the

Life-saving surgery, which, as in the case of breast cancer, can mean a partial or complete removal of the afflicted breast, or a stunt in the heart, a new heart valve or even a pacemaker, can change a woman's relation towards her body. It can result in a changed body image and self-concept. In my research key aspects of body image, such as physical performance, physical appearance, figure, body contact and hygiene are taken up³². Referring to physical activities or performances, I focused on several issues including:

1. physical activities during and after primary therapy;
2. motives for physical activity;
3. restrictions felt by individual when being physically active;
4. athletic aims;
5. support through others when exercising; and
6. the 'private body' in the public space.


'problem of speechlessness'. She argues that the body is a very touchy topic, especially when talking about intimacy and sexuality. In this case language patterns to express them are often missing. This could be seen in many of my interviews, which are connected to the loss of a sexualized body part, the breast, recalling deviant events and emotions. Although most women interviewed seemingly 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. The problem of speechlessness did not appear in the interviews with female heart patients.

³² These are items of body image according to Joachim Mrazek and Ilse Hartmann, "Selbstkonzept und Körperkonzept" in *Bewegungswelt von Kindern und Jugendlichen*, eds. Wolfgang Brettschneider et al., (Schorndorf: Hofmann, 1989), 218.

Not all these aspects can be dealt with in this article. Here I will focus on the first, second and sixth issues but will first start with the significance of the surgery scar.

The surgery scar: A symbol of pain and loss

The surgery scar takes on great significance for breast cancer survivors. It doesn't seem to be of such importance to heart patients whose scars usually are quite small. However, the scar plays a major role in the relation of the patients 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 about 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.

As already mentioned, for heart patients the scar does not have the same significance as for breast cancer patients. It is much smaller, and no body part is missing – a body part connected to sexuality and femininity. In coping with breast cancer, breast prostheses and breast reconstructions *can* remedy the 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 did this for exercising. Mrs. Müller, who first was not in favor of such surgery, decided to have it because she could continue her sports

activities and continue to wear her clothes:

Mrs. Müller: (...) 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 might fall out or such. I thought about it for a long time. My first thought was, I never will have a reconstruction. (...) that is somehow, (very low voice), one has to be very self-conscious, when a breast is amputated (...) I still see it that way (...) and I always thought 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 would not be noticed. Especially in the early months and years after surgery the women had a tendency to wear the prostheses every time they left their home. But in some cases this changed over the years³³.

Physical Activity, Exercise and Sports

To some extent physical activity has already been mentioned in the examples of the interviewed women. The women's athletic or exercise experience prior to their illness was very mixed. Some had been involved in activities from their childhood or adolescence on, or had started after their children were old enough to be left alone, while others had no pre-experience besides their physical education classes a long time ago. This was especially the case for the heart patients. Studies with healthy people show that physical activities can have a positive impact on how we experience our body³⁴. But what is the relationship of breast cancer

³³ 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. Whilst interesting I will not discuss this in detail here.

³⁴ See for example Joachim Mrazek and Ilse Hartmann "Selbstkonzept und

patients to exercise? Doesn't it remind them constantly of their physical restrictions? One focus of the research is the importance of physical activity and sports in their lives. Does it (still) play a role at all, and if so, why, and how does it affect the women's relationship towards their bodies? What exercises or sports do they prefer? With whom do they do them? Do they do them in public space? What are their athletic goals? Each of these aspects is looked at briefly in this section.

Especially for those women who had been active before their disease broke out, being physically active turned out to be of great importance for them during their stay in the hospital and in the course of overall medical treatment, as Mrs. Heim mentions:

Mrs. Heim: (...) we already did our exercise in the morning, and I have to say that these were rather good times; I did recover out there.

Mrs. Heim also was already physically active before she was diagnosed with breast cancer. Among her activities were walking, bicycling, hiking and rope jumping. Walking became an essential part of her life during her therapy. Even when she was still in the hospital and needed drainages, she left the hospital to spend some time outside in nature. She increased the length of her walks to up to 90 minutes. She mentioned that it was extremely important for her to be outside, but stressed the importance of the exercise itself as well. This also can be seen in her efforts to exercise by walking up the hospital stairs until she could manage them with ease.

Mrs. Heim: (...) I put the drainage bottles into the pocket of my track suit und started walking.

A.: Were you allowed to do this officially or did you do it on your own?

Mrs. Heim: I just did it and told them and then they allowed it. And it was always so nice – the three bottles and the others were

hanging like a purse. And then they said, “Are you packing your purse?” Yes, and then I went up and down the staircase. (...) Yes, and on the fifth day, after the tubes had been removed, then I went up into the vineyards. Everyday a bit further. It was very important to walk, to stand on one’s feet.

Just like Mrs. Heim, Mrs. Schmidt felt the urge for activity in the hospital:

Well, already in the hospital, still with these lymph drainages in my coat, in my bathrobe, I did these stair exercises. No one had told me to, and I always climbed in the hospital, and afterwards, when my husband came to visit me, I told him, ‘Now I can already walk up two floors in a row.’

For Mrs. Müller, too, activity was a very important part of her life. She said 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 (...) Because I thought I live directly next to the park (...). Well, then I thought, well, I’ll do that (talks softly). 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.

Mrs. Mehrer noticed that at the end of her chemo it was getting more and more difficult for her to do her activities, so she changed her program:

At the end of the therapy I had no more energy. I could no longer play tennis, because I had radiation. And then I got a swollen

arm. And I could not run anymore because I could not breathe. Then I sat on my stationary bike at home and cycled very slowly, and I went for a walk to get some fresh air. [Laughing.] At that time I was very worn-out.

For these women exercising was already extremely important during their stay in the hospital and during treatment. Walking, for instance, meant mobility for Mrs. Heim and Mrs. Schneider, and not being restricted to a bed and thus being victims of their cancer. Mrs. Müller's crossing of the lake had a similar function, but also was important for her self-confidence. She could see that she was still able to accomplish the tasks that she had done before the outbreak of her disease.

The experience of heart patients was very different from the breast cancer survivors. Except for one heart patient, all of them went to a rehabilitation center after their stay in the hospital. Here they were confronted with exercise and for many of them it was the first time for doing activities after many years.

Mrs. Kleinert: It started in the rehab center. There one did certain exercises on a daily basis. Yes, and because it was boring, I went for walks in the afternoons. I exercised a lot there.

Mrs. Braun: (...) every week day we had half an hour of heart exercise. And then before breakfast we went walking for half an hour and in the afternoon again for one and a half hours.

All the women interviewed exercise regularly a few times a week and emphasized how important it was for them. Mrs. Heim resumed her pre-surgery activity habits little by little after she returned home. At first it was mainly walking, despite the fatigue she felt.

When I was tired, I lay down for some time and slept and then went into the woods. That was really nice and it really picked me up. So it was good. Yes, that was the confirmation.

Mrs. Schwarz, who already was very active before the outbreak of her cancer, changed her activities. Before her illness she mainly worked out in a fitness studio; afterwards she changed to walking, jogging and yoga:

Mrs. Schwarz: Yes, I do sports. Now not anymore in a studio. I quit, it was too loud. I changed through my illness. Now I do yoga every morning after I get up for half an hour. I also attend a yoga class once a week, (...) and I run between three and five times a week, (...). But it is different every time. Sometimes I run, when I want to and sometimes go for a walk or do Nordic walking. It depends on how I feel. If I don't feel so good, then I walk, there I can follow my thoughts. When I run, I have to concentrate more, it is more exhausting for me.

All women asked told me how important exercise was for them. An extreme example was Mrs. Kleinert, who immediately after her heart attack decided to change her life. Before the heart attack she did not like to exercise. She described herself as a "sport grouch". Now exercise dictates her life. After her time in the rehabilitation center she started to go swimming every morning between 6 and 7 am; additionally she visits her heart sport class twice a week and does some walking.

Mrs. Kleinert: (...) And then I said, ok, when I come back, well running is not really what I like, that's why I go swimming on a regular base, and then twice a week my heart sport, (...) and then I also walk with a colleague sometimes in the evenings after work.

A.: You did buy a stationary bike?

Mrs. Kleinert: Yes, I do have this, too. But I have to admit I am too lazy. When I come home, then it would be too much energy for me to use the stationary.

A.: And when do you swim?

Mrs. Kleinert: In the morning between 6 and 7 am. (...)

Mrs. Keinert: (very definite): Because I had told myself, this is a daily must and after rehab I first told myself to go swimming 3 to 4 times a week, and somehow it turned into daily. Now I even sometimes swim before I attend the heart class. And Sundays I go about 80% of the time. Somehow I miss something when I don't go.

A.: How long do you swim?

Mrs. Kleinert: Between 45 and 60 minutes. Mrs. Kleinert also is planning to do some cross-training, but she does not have enough time.

The question arises as to why these women are physically active. The main arguments that the women gave for being active were weight control, health, fitness, prevention of aging, motor skills, socializing and pleasure. All these aspects are usually also mentioned by healthy persons. Very much connected with the reasons for exercising are the effects they can feel through exercising. Some of them reflect the reasons. Both breast cancer survivors and heart patients mentioned: fitness, increase in performance, general well being, relaxation, recovery, and physical and mental disease management. Additionally the breast cancer patients referred to a rising self confidence and a better aesthetic of the body through sports. For the female heart patients it was important to learn to deal with their physical limits through exercising.

The private body in the public space

In Germany physical activity very often is connected to situations where one has to show one's 'private body' (changing rooms, showers, saunas, swimming, and nudist beaches). Many breast cancer patients also think about how others react when noticing that one breast is missing, or seeing their scars or lymphedema. Consequently it is not easy for them when they find themselves – prepared or unprepared – in situations in which their operated-on body is revealed to others. This is especially the case when they visit a sauna³⁵, go to nudist beaches, swim naked, sunbathe topless, or take group showers after their exercise classes. These activities were part of the lives of some of the patients before their illness. Again, the interviews with the heart patients did not reveal as many details. To go to the sauna with heart disease is usually not recommended by doctors. And none of my heart-disease interview partners went to nude beaches or sun bathed topless before their illness, nor did any of them

³⁵ It should be mentioned that in Germany—different to some other cultures - people do not wear any clothes in the sauna.

mention the changing rooms or showers as a problem.

Mrs. Kluge tells of an experience with her running partners – 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, 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 way as they do naked. And then one said, “That’s a very funny and easy one, it looks great and the breast has not been cut off completely. There is still a little mound; it’s done very 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 breast wasn’t as shocking as expected, rather the contrary – they dealt with it very positively and in a relaxed manner. This differs from the example of the women in the water gymnastics group – they looked at the scar with interest, commented on it accordingly and then the topic seemed to be concluded.

For Mrs. Müller, who meanwhile 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:

Mrs Müller: No, I will do it in any case. Yes, I have done it for many years (...), well, it is a lake with a free-body culture beach. It is very nice, and I won’t give up such a thing! 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 would not let herself be restricted by the condition and by that which was visible. In the beginning she still tried to conceal the scar by covering it with a towel. But once the scar changed she got used to it, and she did not hide it anymore. An interview partner who occasionally swam in a naked area before her cancer wore a bathing suit at these places during her first stay after the operation. However, after she noticed a single-breasted woman there sunbathing naked, she felt a great relief. Firstly it was confirmation that other women had the same problem as she did, and also it showed her that there were others affected who were able to live with their illness publicly, so that they didn't have to be ashamed walking around naked on a nude beach.

I was with friends at the (...) a nudist beach 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 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 what should I say, this was the first time, I thought it was great.

That the public showing of the divested bust is something different in a group of affected or unaffected women than in a mixed-sex group with men was noted by Mrs. Heinzmann. She said that whilst there were many things that she has continued doing after her sickness, a visit to a mixed sauna was not one of them. Furthermore she added that she now avoided mixed showers when camping:

(...) at a camping site, and then I have to use a mixed shower, and I go in, and if there are some [men], I leave again. I cannot do that, I can't.

But there are also women who refuse to reveal their scar openly in public. This has nothing to do with age. Bettina, the youngest interview partner, for example, rejected lying on the beach single breasted or visiting the sauna, even if only women are present:

I don't do it anymore. Well, I did it at the beach, but I don't do it anymore. No (...). Sauna, too. I am not self-confident enough to lie down with one breast somewhere. I would not do that.

A.: And among women or girlfriends?

Bettina: No, no. I would not feel good. No, I wouldn't do it.

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 is for breast cancer patients but is also attended by a few healthy women. The latter choose preferentially the few single changing rooms, whereas the breast cancer survivors predominately change in the communal cubicle. Furthermore, the healthy women would often wait and stay longer in the pool to avoid seeing the others without their swimming suits under the shower – something which is normal in Germany when taking showers after exercise classes.

Conclusion: The Wounded Female Bodies

Both the heart and the breast have a special role in western society. Due to their visibility and invisibility, their sexual code or lack of it, there are differences in the construction of the illnesses connected to them. The female breast is 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, although more women suffer from heart disease than from breast cancer.

The hidden heart is also an important symbol in western languages, art and even everyday life. Still, heart disease does not share such a negative metaphorization as cancer, in particular breast cancer, which often is seen as the dark and evil in the body. Although cardiac disease also implies a certain weakness of the individual (for instance, that one has neglected a certain responsibility to control risk factors), nevertheless, there is no disgrace involved. Heart disease, furthermore, is seen as

mechanical failure, and is free of the taboo associated with cancer. In fact, it is often connected with males. In Germany it is called the 'manager disease'. Successful, ambitious men often seem to suffer from it³⁶. The different cultural construction of breast cancer and heart disease influences what a society considers a stigma and what not. Thus it also affects afflicted women, how they perceive their illness and how they deal with it in privacy as well as in public and their access to their own lived body.

As shown throughout this article, breast cancer survivors face different problems than female heart patients. This is also the case when it comes to sport performance or exercising. However, generally speaking, both groups of the women that were interviewed emphasized that by exercising they are contributing to both their physical and mental well-being. This definitely can be seen as a positive impact on their feelings of achievement, body image and self-confidence. And it also implies a social aspect: through exercising they fight passivity – not being bound to the sickroom and to the doctor's decision, but being active and thus contribute to the healing process, to fight against the illness, or just to escape from it for a few minutes. Through participation in sport or physical activities the interviewed women enter the 'real world', which is not of the world of sick people, but of healthy ones.

Despite the similarities in the answers, a difference could be noticed in the reasons for being active. Whereas the breast cancer survivors mentioned how important physical activity was for their self-confidence and body aesthetics, the main difference to the heart patients was that they now could feel their physical limits – limits they need to know in order to manage life and survive. The other difference could be noticed with respect to the 'private body in the public space,' which is clearly connected with the stigmatization of breast cancer. It revealed the inner conflict of breast cancer survivors when showing their naked body or their operated-on breasts publicly at beaches, in saunas or the locker room of their gym where they make their changed breasts or scar visible to

³⁶ Sontag, Susan, *Illness as Metaphor*. (New York: Farar, Strauss and Giraux, 1978), 9.

others. The interviews showed that age did not play any role.

To conclude: with regard to public appearance it can be seen that for all these women, physical activities have helped them to re-enter the ‘real world’ again or just stay a part of it, and thus to some extent to escape from exclusion. They are fighting passivity and are demonstrating that despite their illness they have not given up, that they are part of this world and participating in it just like any other woman, yet still showing their difference, be it when exercising with drainage bottles, or with or without a wig, and thus showing parts of their private, ‘lived’ body. Whichever illness the interviewed women suffered from, they will never forget that they have 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 – wounded³⁷.

In some way my interview partners will always stay ‘eternally wounded women’ as well as ‘wounded storytellers,’ to borrow the titles of books by Patricia A. Vertinsky (1989) and Arthur W. Frank (1995)³⁸.

³⁷ Quote from an interviewed breast cancer survivor.

³⁸ Vertinsky makes the historical suffering of active women public and Frank tells us how patients with a chronic illness feel about their suffering body as their wounded body.

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