WHO OWNS THE BREAST?

Riekje Elema

Thesis AMMA Programme
University of Amsterdam
June 2001
ACKNOWLEDGEMENTS

First, I like to thank the women who were willing to be interviewed and were so open in their talks. Their experiences gave body to this thesis. The interviews were very special to me and I will always remember them. I hope they are content with what I wrote and find themselves back in issues I discussed.

I would also like to thank my key-informants for making the time and sharing their knowledge about the topic.

It was a struggle that took too long. Besides that, the topic for my thesis changed several times. I am in debt to my supervisor, Els van Dongen, for her support in getting my thoughts and ideas clear and focused again. Without her, I would not have been able to do it.

I also like to thank Ria Reis for calling me again when she did not hear from me for a long time. All other people of the University who made it possible to finish my study have my gratitude.

Then I am thankful to my colleagues who kept on stimulating me to start again and finish my thesis.

A special thanks to my friend Jackie who commented on the drafts. For me this was very useful and helped me a lot.

Last but not least, I want to thank my family, friends and especially my sister Dieuwer who kept supported me during the troublesome times I went through in the last two years.

Thank you all!
Look to this day for it is life, the very life of life.
In its brief course lie all the realities and truths of existence:
the joy of growth, the splendour of action, the glory of power.
For yesterday is but a memory and tomorrow is only a vision.
But today well lived makes every yesterday a memory of happiness
and every tomorrow a vision of hope.
Look well, therefore, to this day.
EXECUTIVE SUMMARY

This study was undertaken as partial fulfilment of the degree of Master in Medical Anthropology. It set out to explore how a group of Dutch women coped with breast cancer.

This study is a qualitative descriptive one based on data from interviews with women who have breast cancer. Information was gathered through in-depth interviews. One focus group discussion was conducted. Additional information was obtained through interviews with key-informants. The title “Who owns the breast” was chosen because of the many controversies around this topic.

Breast cancer is the most common kind of cancer among women in the Netherlands. There are around 70,000 women with breast cancer, of whom around 3,500 die every year.

In our culture, breasts have a certain function, that is mainly sexual or as a symbol of femininity. With breast cancer, the most threatening discourse is not always the medical one, but often the prevailing cultural one.

Dealing with breast cancer is a major traumatic life event, affecting women and their surroundings. In this process, women are faced with a life-threatening disease. Women with breast cancer, as members of a particular culture, are confronted with norms and values about how a female body should be: a standard to which they, because of the treatment, can no longer live up to. Nevertheless, they have to cope and adapt to their new body images. How women cope with this depends on several factors. These are among others: the way they look at their body, the source of their self-esteem, their social network and the way they are treated by health professionals. All these factors are interrelated with the sociological, cultural, economic and political surroundings the women are part of and live in.
In total ten women were interviewed. Five of them had finished their treatment for more than two years. The others five were still in the middle of their treatment. When these women heard they had breast cancer, they were devastated and their struggle with cancer started. All of them had to go through a diversity of treatments, of which each brought its own problems. All women were faced with the fact that their body changed because of either a lumpectomy or a mastectomy. Their feelings of femininity, attractiveness and sexuality remained, although some of them now only have one breast. Time was an important factor in this. They all mentioned that they changed in a positive way because of what happened to them. They felt that they became better persons in the sense that they were better balanced, less troubled with what people around them thought and enjoying life more intensely.

All women valued the support they got from the people around them, although some mentioned that the period after the treatment was very difficult and complicated. This was not always realised by the people around them.

The interaction with the health professionals was satisfactory for most of the women. However, one woman felt that the support given was very poor.

Their fight against breast cancer was not only a private one. The women interviewed had to cope with what our culture thinks about breasts and physical appearance and this made it more complicated for them, being members of this same culture. Each one decided how she wanted to continue her life, be it through having a reconstruction, wearing a prosthesis or nothing. They chose the path that suited them best and that is also the way it should be, because in the end they are the ones who own the breast.
**TABLE OF CONTENTS**

**ACKNOWLEDGEMENTS** ........................................................................................................... I

**EXECUTIVE SUMMARY** ........................................................................................................ IV

**TABLE OF CONTENTS** ........................................................................................................... V

**INTRODUCTION** ....................................................................................................................... 5

**LITERATURE REVIEW** ............................................................................................................ 7
  - **INTRODUCTION** ............................................................................................................... 7
  - **INDIVIDUAL BODY** ........................................................................................................... 8
  - **SOCIAL BODY** .................................................................................................................. 16
  - **BODY POLITICS** ............................................................................................................... 18
  - **FINAL REMARKS** ............................................................................................................ 22

**RESEARCH OBJECTIVES AND METHODS** .......................................................................... 23
  - **CRITICAL NOTES** ............................................................................................................ 25

**FINDINGS AND INTERPRETATION** ....................................................................................... 27
  - **INTRODUCTION** ............................................................................................................... 27
  - **DEALING WITH CANCER** .................................................................................................. 27
  - **SUPPORT** .......................................................................................................................... 31
  - **BODY IMAGE** .................................................................................................................. 33
  - **SEXUALITY** ...................................................................................................................... 38
  - **PROCESS OF CHANGE** ................................................................................................... 40
  - **FEAR FOR THE FUTURE** .................................................................................................. 42
  - **CONTACTS WITH HEALTH PROFESSIONALS** ............................................................... 43
  - **PROSTHESIS AND RECONSTRUCTION** .......................................................................... 44
  - **INVOLVEMENT IN AN ORGANISATION** .......................................................................... 48
  - **SUMMARY** ....................................................................................................................... 49

**DISCUSSION** .......................................................................................................................... 51
  - **WOMEN AND THEIR BODIES** ......................................................................................... 52
  - **HOW DID THE WOMEN COPE?** .................................................................................... 54
  - **NEW PERSONS?** ............................................................................................................... 57
  - **WOMEN AND THEIR DOCTORS** ...................................................................................... 58
  - **BREASTS, A PUBLIC GOOD?** ........................................................................................... 60

**CONCLUSIONS** ....................................................................................................................... 62

**REFERENCES** .......................................................................................................................... 63

**ANNEX 1. GLOSSARY OF TERMS** ......................................................................................... 67

**ANNEX 2. TOPIC GUIDE** ........................................................................................................ 68
INTRODUCTION

In each society, the body has a social as well as a physical reality. That is the shape, size and adornments of the body are ways of communicating information about the owner’s position in society. These realities differ between cultures and between different groups in a culture. In each society, there are culturally defined notions of beauty, and of the optimal size and shape of the body. Therefore, body shape and size are possibly altered to fit in with the culturally prescribed pattern.

Cultural ideas of what is attractive reflect normative expectations of the female and male body. The way men and women are expected to look is attached to what their gender roles are. In Western society, thinness equates with beauty. Particular parts of the female body that play a major role are the breasts of a woman. Breasts, especially for men, are sexual ornaments, the crown jewels of femininity.

One can say that the body is commercialised. Media, such as television and magazines, spend enormous amounts of money and time on what is “hot”, what is “in”, beauty contests, how people should look. Over the last decades the body became a consumer good.

Bodily dysfunction is perhaps the most common threat to the appealing belief that one controls one’s destiny, but then, in how far are we in control of our bodies? If one must believe the many authors one only can conclude that we are not what so ever. We are controlled either by doctors, epidemiologists, anthropologists or by our own surrounding (friends and family). All have something to say or dictate something to us, in this context about the patients or act upon the sickness of patients in a controlling way. We, as patients, either are seen as acted-upon objects, we are marginalised or stigmatised, are overpowered by the medical system. We are seen as passive receivers of treatment to which we have to comply but when we do not get better we have to blame ourselves, for not responding well to the treatment.
We are controlled by our own cultural values and norms and have to comply with the standards. When suddenly we are sick or missing a breast, we have to see ourselves as victims as deformed and as less worthy individuals.

Of course there is an element of truth in the above mentioned. We, as individuals, are part of a bigger whole, our society, and there are controlling mechanisms in place. In general, we are raised in a society where the biomedical belief system is favoured and based upon that system, our health system is created. We partly depend on the medical professionals, because they know more about some therapies for sicknesses than lay people do. We also partly depend on the others in our surroundings being social beings. Nevertheless, we are also individuals with our own background, knowledge, beliefs and we are for sure not only passive receivers. We, as individuals, play an active role in the process of sickness and health and we do not necessarily have to be marginalised or stigmatised or become less worthy individuals.

This study investigates how women cope with breast cancer and the results of treatment, namely mastectomy. It will try to give insight into what women experience when diagnosed with breast cancer. What kind of factors play a role in being able to cope with the disease? It may also serve to increase caregiver sensitivity to the fact that there are so many differences in how women experience breast cancer. Last but not least, it hopefully tells us something about how our culture is dealing with women with breast cancer.
LITERATURE REVIEW

Introduction

Historically beauty was treated as a virtue, which was associated with the female sex. Since Plato, feminine beauty was idealised, representing moral or spiritual qualities. In the medieval culture, feminine beauty was a symbol worth fighting or dying for. In the Renaissance female sex was linked with the female nude representing the divine beauty in its purest form. In the 19th century romantic poets, novelists and philosophers got their inspiration from beauty adopting beautiful women as their muse. By the twentieth century, the cultivation of appearance became a central concern for women of different classes, regions and ethnic groups.

The meaning attributed to the breasts throughout history has rarely expressed women’s feelings about themselves. Only recently, have women begun to talk openly about their breasts. They have spoken of the adolescent’s embarrassed pride, the adult women’s erotic pleasure, nursing mother’s joy, the breast cancer patient’s suffering, the brassiere designer’s hype and the consumer’s frustrations; the woman with big breasts who wishes they were smaller and visa versa. How a woman regards her breasts might be a good indicator of her personal self-esteem, as well as of the collective status of women in general (Yalom, 1997).

In the western world, breasts are probably the most visible symbol of femininity and, therefore central to women’s identity and bodily self. More than any other body part, breasts are “up for judgement”, problematic and subject to various forms of correction.

As already mentioned above, over the last centuries, breasts were given different meanings. Today, in the twentieth century, the word “breast” conjures up sexual scenarios for both men and women, as well as the reality of breast cancer for all too many women.
This literature review will look at different issues related to the body, breasts and breast cancer. To structure the discussion, I will use a model introduced by Scheper-Hughes and Lock (1987). In this model, the interaction of the body with health/illness on three different levels is described. On the three levels, the bodies are separate but inter-linking entities. The first body is the *individual body*, understood as the lived experience of the body self, the embodied experience and views of the individual sufferer. The second body is the *social body* where symbolic, representational use of the body and body products is used to sustain particular views of society and social relations. The third body, the *body politics*, which is seen as to control, regulate and survey the conduct of bodies at individual and group level in order to maintain social stability. The individual body should be seen as the most immediate, the proximate terrain where social truths and social contradictions are played out, as well as a locus of personal and social resistance, creativity and struggle.

Our own body is in the world as the heart is in the organism: it keeps the visible spectacle constantly alive, it breathes life into it and sustains it inwardly, and with it forms a system.  
(M. Merleau-Ponty, year unknown)

**Individual body**

There is a tendency for the body to become increasingly central to the modern person’s sense of self-esteem. Both at academic and popular level there is a rise of interest in the body. Growing numbers of people are increasingly concerned with the health, shape and appearance of their own bodies as expressions of individual identity. Investing in the body provides people with a means of self-expression and a way of potentially feeling good and is increasing the influence they have over their bodies. Investment in the body also has its limitations. Bodies age and decay, and the reality of disease and death are particularly disturbing to modern people who are concerned with a self-identity that has at its centre the body (Shilling, 1993).
Functions of the body are diverse and body image is in the centre. As Helman (1994) states, body image is something that each individual acquired as part of growing up in a particular family, culture or society. Body image can be defined as the collective attitudes, feelings and fantasies about a body, as well as the matter in which a person has learnt to organise and integrate body experiences. Helman divides the concept of body image in four main areas:

1. Beliefs about the optimal shape, size and adornments of the body, in the sense that these are ways of communicating information about the person’s position in society. He also mentions that this includes bodily gestures and postures, the “body language” of a person.

2. Beliefs about the boundaries of the body. Boundaries of the body and the ‘self’, the sense of personal identity possibly are not the same. The latter extends far beyond the first. The ‘self’ is surrounded by a series of symbolic skins defining the intimate, personal, social and public space.

3. Beliefs around the inner structure of the body. Concepts of the inner structure of the body are for many people a matter of speculation and vary a lot.

4. Beliefs about how the body functions. It might be seen as a machine, with pumps and tubes linking everything together.

When looking at the body and illness, it is important to focus on how the body deals and copes with the physical manifestations first, before one looks at how the person copes with disruptions in the social life. Bodies change in illness. Chronic illness (in this case breast cancer) also involves changes in self-conceptions that are reciprocal to bodily experiences, feelings and actions. It transforms the person. Kelly and Field (1996) mention, that as an individual moves from situation to situation, as one’s body changes and as one’s illness develops, there is still an important sense that one is the same person one was before the body altered, though in a different social situation. The body, which in many social situations is a taken for granted aspect of the person, ceases to be taken for granted, once it malfunctions and becomes more prominent in the consciousness of self and the others.
No one will argue about the fact that a mastectomy is a violation of the body – an amputation of a body part. No one will argue that disease and trauma in general have a negative impact upon body image. Several studies have shown that disfigurement to the body, related to amputation, results in distortions in body image and sexual functioning (Derogatis, 1980). As one woman said, the loss of a breast had become a metonym for the loss of womanliness. A reconstruction of the breast could not by itself recover this for her. Her own inner sense of femaleness had changed profoundly – through an accretion of related concerns, each of which had some bearing on this basic issue of sexual body image (Couser, 1997).

An issue very relevant to the topic breast cancer and mastectomy is bodily integrity. Breast cancer, like some other diseases, may radically undermine a patient’s sense of self. Bodily integrity can be defined as the whole, non-violated (undamaged) body. For me, this includes the physical, social and mental wholeness of the body. In exploring the concept of bodily integrity in relation to the subject, one should look at the emotions involved. Emotions play a very important role. Emotions affect the way an individual perceives what happens to her/him and in the end determine what an individual feels. Scheper-Hughes and Lock (1987) mention that insofar emotions entail feelings and cognitive orientations, public morality and cultural ideology, they provide an important ‘missing link’ capable of bridging mind and body, individual and society. Emotions are catalysts that transform knowledge into human understanding. Human events literally are boiling with emotions. They also tell us that they think that emotions and feelings are never free of cultural shaping and cultural meaning.

Women have emotions in their breasts. Emotions are also physical experiences. This is not only when feelings are erotic. Women feel their breasts when they hold a child, breastfeed. Besides that, the breast has a symbolic value for women. Having to miss a breast hurts, it is separating from a part of you, you would have liked to keep.
All women will handle this in their own way. Lorde (1985), a breast cancer patient herself, describes an amputation as a physical and psychological reality that has to be integrated and internalised into a new feeling of self-esteem. Missing a breast still gives feelings of sorrow and sadness, but it does not always control her anymore. For other women this might be completely different. In the literature are ample examples of the devastating effects of breast cancer and mastectomy. Women feel mutilated, incomplete and may decide to have a reconstruction done (Couser, 1997). A very common phenomenon is “downward comparison”. Women tend to compare themselves with others who are worse off. This might help them with coping better with their own suffering and pain (Fabian and Warren, 1992).

Self-esteem is the sum of all that a person feels about himself/herself. It is a fluid, dynamic concept capable of changing from positive to negative and back again. Shain (1980) describes a model of self-esteem with four components. These components include 1. The body self: which has a functional (what can I do?) and an aesthetic (how do I look?) subfactor. 2. The interpersonal self: which is comprised of both social and acquaintance relations as well as intimate, sexual interactions. 3. The achieving self: which contain elements of work or competition efforts such as carrier and school behaviour and 4. The identification self: which is comprised of those attitudes and behaviour that are related to spiritual, ethical or ethnic matters. These four components work in conjunction with each other and form a pattern experienced as self-esteem. At different times and due to different circumstances, a person may experience a sense of depreciation, loss or insult in any one of the four components. One person might have all four components in balance. Another might heavily lean on one of the components. Being confronted with breast cancer and all its consequences does influence self-esteem and can disturb this equilibrium between the four components.

The adjustment to living with what could be a life-threatening diagnosis is enormous, not only for the woman herself, but also for her family, children and significant others.
Learning to live with the uncertainty is very difficult; learning to trust your body again when it betrayed you is very hard. Psychologically, the hardest time is after the treatment is completed. Breast cancer is rarely considered cured – because having ‘had’ cancer usually means being susceptible to recurrence. On the other hand, illness takes away parts of your life but in doing so it gives you the opportunity to choose the life you want to lead, as opposed to living out the one you have simply accumulated over the years (Couser, 1997). Lorde (1985) commented that breast cancer, with the awareness of mortality and the mastectomy, can still be a gateway, although conquered in a very cruel way, in the search of one’s own power and knowledge. She had the feeling that, while in the process of losing a breast, she became more and more a complete human being.

Fig 1. Model of impact of breast cancers on feminine self-concept (Derogatis, 1980)
The model is one way of explaining the complexity of coping with breast cancer, the relationship between different factors involved. In the model, body image and sexual functioning are represented as being sub-components of self-image and psychological adjustment, respectively; and each in turn an integral aspect of the other, just as we see self-concept and psychological adjustment being integrally related.

In a study by Kravdal (2001) it is mentioned that married women have a better survival rate than never married, divorced/separated or widowed women. Married here relates to the care and support provided by family members, better financial circumstances among the married and the tendency to avoid risky and unhealthy behaviour because of family responsibilities or social control.

Derogatis (1980) explains that certain important mediating variables are illustrated as functioning to amplify or moderate the effects of the disease. Patients with a history of stable adjustment prior to the disease, as well as those who are well informed and have developed constructive attitude postures are likely to do better. Similar for women who are older and who possess a balanced or androgynous gender role definition appear to be less psychologically devastated by the disease. Nonetheless, breast cancer possesses the capacity for being a particularly catastrophic experience, by virtue of the direct impact it has on essential components of the woman’s identity – her genital organs. They relate to her physical integrity and the sense of wholeness, and because they form the foundation for her definition as a sexual being.

Sexuality is one of the issues least discussed. Women find it difficult to discuss, especially because it is related to feelings they themselves are only partly aware of. They lost a breast, a body part, very much associated with sexuality and often think that they are less sexually attractive. They might also not feel the need for having any sexual relationship (Love, 1995).
Sexuality is everything you are, from your sense of humour to your intellect, to the way you conduct yourself in everyday activities. It is how you make your partner feel emotionally in bed, as opposed to what a body part feels like. Sexuality is not only physical, having certain body parts (Fabian and Warren, 1992).

Many women have problems with sexuality and intimacy when they have breast cancer. Not only do they feel that their body has abandoned them, but also the whole therapy might have damaged the bodily integrity. They have been touched by strangers for months and might feel raped. Because of that, they might forget that their own bodies also gave them pleasure (Love, 1995). Breasts are a source of pleasure for women, a part of their body that distances them, at least partly, from cultural norms of beauty (Davis, 1997).

Some women discover that a sexual relationship becomes more important after a mastectomy. This has to do with re-establishing their feelings of self-esteem and well being. It is also possible that the sexual experience is changing. Erotic feelings, first experienced through the breasts might now be coming much more from the orgasm. Other women miss the stimulation of amputated breast so much that the other breast should also not be touched anymore.

Sexuality can also change because of the treatment the women underwent. It is sometimes difficult to separate the physical aspects from the emotional ones (Love, 1995). One of the treatments, chemotherapy, induces menopause prematurely, and the patient comes to realise that the loss of her breast represents a change of life beyond the expertise of her physician, and even the understanding of husband/family (Couser, 1997).

Radical mastectomy was developed by William Halsted in the late nineteenth century and became the standard procedure for treating breast cancer. The development of additional therapy, such as radiation, chemotherapy and hormone therapy started in the late 19th century.
It was only in the late seventies that women started to take an active role in arguing against these radical methods. Before that, one could say that women just followed the orders of the medical professionals.

In the course of cancer, there are many contacts with the medical professionals. It is known that the good interaction between medical professional and patient is extremely important (Helman, 1994). Trusting the health professional is essential. Patients’ concepts of trust vary from technical competence, interpersonal competence, responsibility, control, caring and confidentiality. In a study by Mechanic and Meyer (2000), women with breast cancer generally trusted their medical doctors, this because women felt a strong need to be able to trust their physician in the light of the life-threatening nature of their disease.

The area of competence of the health professional is central to the patient (Mechanic & Meyer, 2000). Patients will be more inclined to get better when they are provided with satisfactory explanations for what bothers them, sense care and concern among those around them and are helped to achieve a sense of mastery or control over their illness and its symptoms (Couser, 1997). There are ample examples in which the interaction between health professionals and women with breast cancer was problematic and lead to the creation of additional anxiety and delay in treatment (Vonkeman, 2001; Couser, 1997; Brederode and Floor, 1977; Meijer-Linstra, 2000).

Whatever the choices the women make regarding treatment, prosthesis, or breast reconstruction, all choose to own their illnesses rather than to pass on as healthy or physically intact (Couser, 1997). Choice of treatment reflects personal values and circumstances rather than medical mandate. The individual woman’s desire to have reconstruction does not mean that she actually decides to have it done. Women who have breast cancer are often grateful for the availability of reconstruction, although certainly not all women choose them after mastectomy, with the hope of a normal, relatively unscarred body.
Social Body

Scheper-Hughes and Lock (1987) describe the social body as a symbol, important in our society. Murphy (1995) comments that the body has become so important that we, as a people, do not even realise that its care and nurture have changed from practicality to fetishism. The body must be more than clean; it must have a certain shape. It is not only an aesthetic matter, but also a moral imperative.

The picture or image one has of one’s body includes not just a physical map but a judgement of that body as well. Particular parts of the body may be especially significant in this assessment, especially as we compare it and learn that others compare it with an ideal type. There is a cultural standard of height, weight and shape against which one’s body image is formed. The image requires evaluation, and particular parts of the body such as breasts are central to that assessment, given the attention they receive in the media as well as in talk and conversation. The person takes her body as an object, stands outside herself, and evaluates it based on her perceptions of how others would, or do, evaluate it. She subsequently acts toward her body based on these perceptions of others’ evaluations (White Stewart, 1998).

Illness is a negotiated state that results in a change of identity when others define the person as sick, typically after consulting a medical doctor. When having flu, the person and social network know this is only temporary. In chronic illness, cancer, the self and identity are substantially and permanently altered. How apparent this is for the people around the person remains to be seen. Someone in the early stages of cancer may have had one’s sense of self completely shattered as one ruminates on one’s own mortality but one’s family, neighbours or friends might not realise this. Only when external signs of deterioration are seen, they might adjust their ideas about the person (Kelly and Field, 1996).
Breasts in Western society have a certain function, mainly sexual or as a symbol of femininity. With conditions, such as breast cancer, the disease is always culturally constructed and the most threatening discourse is not always the medical discourse, it is the general cultural discourse that ascribes stigma to a bodily dysfunction. Sontag (1978) has brilliantly illustrated how the cancer discourse has tended to stigmatise and marginalise the ill, condemning them in two senses, simultaneously censuring and sentencing them. Commonly people talk about fight against cancer and cancer victims.

Breast cancer, in a way, doubly stigmatises and marginalises. Firstly, a woman has cancer and secondly, in many cases, a removal of a breast is a consequence of that. That people in our society have problems dealing with cancer is commonly known.

When poets speak of death, they call it the place “without breasts”
(R.G. de la Serna, 1917)

The confrontation with death in a society that likes to be in control of everything is difficult to handle. Dealing with a deformation of the body, in the case of a mastectomy, is another problem. This, in the eyes of society, makes a woman deviant, different from the rest. It contravenes all the values of femininity and beauty.

It is because of this that one often finds the following stereotyping of a woman with breast cancer: a deformed, less sexually attractive, less feminine woman, therefore less worth as an individual. The woman would be rejected by future lovers or abandoned by her partner and somehow less a woman. This stereotype evolves from our cultural linking of a woman’s identity to her attractiveness and worth and of her femininity to her breasts and body. A woman’s value has also been defined in relation to men: How could a woman who is considered “damaged goods” ever attract a man? (Couser, 1997)
According to Fabian and Warren (1992), it is unfortunate that we live in a society that emphasises the female breast and its role in a woman’s sexual attractiveness. Because of this, many women assume that their spouses or lovers – or future spouses or lovers – cannot possibly find them sexy and desirable. Sometimes this becomes a self-fulfilling prophecy if the woman reacts by assuming she is undesirable and acts accordingly. They finish by stating that women who feel that their desirability is based on their breasts are buying into an attitude that is unfair to most men. Husbands and partners greatest concern is invariably centred around their wives health. Loss of breasts is insignificant in comparison.

Breasts have been of interest for medical doctors for as long as people live. One area of interest was the lactation and the other one was disease. If one goes back into history, one will see that in ancient times lactation was an issue addressed in detail by medical doctors. Breast cancer was first mentioned in the Ancient Greek times. It was Galen (129-99 BC), who wrote that melancholic women were more prone to get breast cancer than cheerful ones, an idea that is still existing today. He is also the first who described breast cancer operations, that though adjusted, are still carried out in a similar way at present (Yalom, 1997). One may conclude that the medicalisation of breasts started as early as then. In the following centuries, many medical doctors had something to say about breastfeeding or wet nursing and diseases of the breasts.

**Body Politics**

The relationship between the individual and social bodies concerns more than the metaphor and collective representation of the natural and cultural. They are also about power and control (Schepers-Hughes and Lock, 1987).

---

1 Breasts in non-western societies are less important as sexual objects, breasts are more seen in the view of providing milk for their children, for nurturing. Breasts are more important for children than for men.
When one does a search for the word breast on Internet, there are 1.750.735 hits, the word tits produces 1.218.810 hits. This together is almost three times more in comparison with the male sexual organs (penis and testicles). Breast cancer gives about 700.000 hits and prostate cancer gives +/- 220.000. Lung cancer, the number one cancer amongst men gives around 200.000 hits (Alta Vista Search Engine, 2001). Breast cancer is a hot topic. Many medical institutions put a website on the Internet to give information or advice. This partly has to do with the fact that women, especially in Western countries and particularly in the United States, have been very active in getting it on the political agenda in which they clearly succeeded. It also is related to the fact that breasts and breast cancer are matters close to people’s heart, both men and women worry about it. Breast cancer is in the middle of the political struggle.

Women’s social world and everyday experiences can not be removed from cultural beliefs and definitions about their bodies and are intimately linked with economic and political power structures. Patriarchal culture fetishes woman’s breasts and this puts a premium on at least the appearance of intactness. The issue of visibility arises and is related to the larger issue of women as objects of the male gaze. Although the tumour as such is invisible, the scars and surgery are visible, Through internalisation of the male gaze and values, women evaluate themselves as men evaluate them. This internalisation is transformative; it is the process through which the “structures of society become the structures of our own consciousness (White Stewart, 1998).

Most people, including the medical people, carry around a set of notions about the social position of the cancer patient, in this case a woman with breast cancer. A woman with one breast is considered as deviant. Deviancy, as Durkheim (2000) tells us, is a universal but relative concept, it also is socially defined, socially constructed and varies within the social context.
He continues with stating that social groups make conventions and impose them on others using social sanctions and people as part of a collective, make rules and define what is deviant\(^2\). Last but not least, defining what is deviant and enforcing such as a definition involves power.

In his article about disability, Murphy (1995) argues against the notions of deviancy and stigma. He thinks that disability should not be seen as a type of social deviancy but as a form of liminality. I clearly see a parallel with how women with breast cancer should be seen. People who experience life-threatening illness do not necessarily pass through phases that can be well defined. Liminality should be seen as an enduring and variable state, it does not necessarily have to be a long-term state as Murphy mentioned. It should try to capture something of the subjective experience of illness, rather than to categorise the changes in social relationships (Little et al, 1998). The fact that we have to come with a term as liminality might be due to the introduction of the new paradigm of illness by biomedicine. Whereas illness was seen as a normal part of life in the past, nowadays it is seen as an abnormality. In a way, it is socially constructed by the biomedical system that is very powerful.

Considerable power of the medical profession today depends on the medicalisation of society and the concomitant granting of the virtual monopoly on diagnosis and treatment of illnesses to trained specialists. One manifestation of medical authority is the control of information. The rational for withholding information has to do with the presumed inability of patients to understand or use it, precisely because they are non-professionals and because as patients, they lack “objectivity” in regards to their conditions (Couser, 1997). It also is related to the “discourse of hope” in which the disclosure of information about diagnosis, prognosis and treatment is carefully regulated by the physician.

\(^2\) In Greek mythology, a group of women, the Amazons, cut off their right breast to be able to handle the bow better, a very pragmatic reason. They still had the other breast for feeding their offspring. This was seen as inappropriate, deviant because a woman should have two breasts and not even think about defending themselves against men.
This considerate paternalism is justified on the grounds that doctors know better than their patients what will sustain their hope and ensure their continuing co-operation with treatment regimens. Indirectly, biomedical discourse creates the patient as an acted-upon object in the sense that verbs in the passive voice are used to make the disease process distinct from the patient (states, complains or claims – all of which emphasise the subjective). Physicians, on the other hand, note, find or observe the objective signs of the disease. In this way, the patient’s account of the illness/symptoms is de-authorised (DiGiacomo, 1992). In the case of breast cancer, it is even more complicated because there is hardly any patient account. Most women have no complaints when going to the health professionals. The treatment is making them sick. The issue of power or powerlessness is therefore particularly evident in a disease like breast cancer because one does not feel sick and is totally dependent on “Western technology” for the diagnosis (i.e. X-ray or biopsy).

Modern Western medicine bases its identity on its presumed expertise and humanitarian interest. Collectively and individually physicians establish, exercise and perpetuate their power by means of the development and deployment of specialised languages. Furthermore, although physicians usually rely to some extent on information provided by patients, they assume total responsibility for diagnosis, prognosis and therapy. After a patient presents his or her case to a physician, the role of the patient in conventional medical discourse is to attend to, and to comply with “doctor’s orders”. In the end the doctor knows best and preferably the patient has to adhere to the chosen treatment (Couser, 1997).

Nowadays, more and more patients seek alternative healing methods. The biomedical system has to acknowledge that it is not completely in control of the whole process. Patients, women with breast cancer, are increasingly able to find information through media or the Internet and are better able to speak out for themselves. This reduces the power of the medical professionals and forces them to approach women in the different way.
Final Remarks

There are some critical notes to be made in relation to the way Scheper-Hughes and Lock (1987) developed the concept of the mindful body. In a way, they followed the arguments as the one they criticise, the biomedical discourse. The model might be different, but the assumptions/concepts could be the same. As DiGiacomo (1992) states: we, as anthropologists, might begin to decenter our own narrative self-assurance, by assuming that ill persons have at least the normal capacities for understanding their situation and articulating what they find most salient in it.

In her book “Passion for difference” Moore (1994) explores the concept difference. She mentions that each individual has a personal history and it is at the intersection of this history with the collective situation, discourse and identities that the problematic relationship between structure and praxis and between the social and the individual resides. Discourses are structured through difference and women (and men) take up different subject positions within the same discourse. So there is a multiplicity of femininity and there are multiple ways of being feminine (or masculine) within the same context.
RESEARCH OBJECTIVES AND METHODS

For me, coping with breast cancer and all its consequences was a very traumatic event. Loosing a breast seemed to be the most devastating thing that could happen to me. The sudden realisation that in the future, my body would be permanently different, deviant to what was considered as a normal female body was very troublesome. The feelings of low self-esteem, being damaged and therefore not whole anymore were strong. In the months after, fighting cancer became more and more important and surviving breast cancer, with or without breast, was the aim. I realised that, although in the beginning, loosing my breast seemed the most horrible thing there were other things more important for me. Besides that, I realised that living in a culture where female bodies and especially the breasts are almost a public good, influenced my way of thinking very strongly.

Some writers tell us that a mastectomy makes a woman deformed, less attractive, less feminine and therefore less worthy as an individual. Is it then true that we, the women, get our self-esteem and identity mainly from our bodies? Is it the society in which we live that determines or links a woman’s identity to her attractiveness, her worthiness and femininity to her breasts and body?

My aim is to describe how a group of women coped with their bodies after a mastectomy. What do women having had a mastectomy think about this, what does it do with their ideas about their bodies, feelings of femininity and how do they cope with it? How do they think their partners or other significant others cope with it? Having one breast because of a mastectomy is clearly a deviation of the standards of conventional femininity. How far does this phenomenon, the mastectomy, change the behaviour of women? How do larger cultural ideas influence their perceptions about this?
It is a qualitative descriptive study based on data from tape-recorded, in-depth interviews with women, who have breast cancer. Initially I also wanted to interview their partners, but because of the limited time, decided against this. My own experiences are incorporated. Introspection is an integral part of the whole study. I also used accounts of women from other books and reports either to confirm my findings or to show that there are different ideas.

Two key-informant interviews were conducted. These key-informants were selected based on their expertise in areas relevant to the topic. I met with an oncology nurse and a woman who is running a shop for breast prostheses.

Archival review of available articles, magazines, books and newspapers was carried out throughout the study period, using the libraries, the Internet and visits to the Cancer Information Centre and the Co-ordination Centre for Breast Cancer.

Convenience sampling was used to obtain informants. Interviewees were referred to me by personal contacts, who introduced the study topic to persons of whom they thought might have an interest in participating. Before asking someone to participate in the study, I introduced myself as a graduate student from the University of Amsterdam and explained the purpose of my study. I also expressed my personal interest in the study because of my personal history, that I was a companion in distress. I took this approach because I felt and still feel more like a companion in distress than an experience expert, though the former does not exclude the latter. This facilitated the process immensely. I discussed confidentiality and asked if I could tape the interview before starting the interview. I arranged the interview time and place at the convenience of the interviewee.

Interviews were conducted using an interview guide (see annex 2). Five interviews were conducted in the informant homes.
Two were conducted in the hospital. One focus group discussion was conducted with women who underwent either a mastectomy or lumpectomy.

At the time of the interviews, the women in the in-depth interviews all had finished their treatment. One had just recently finished hers, the others for more than three years to a max. of 22 years. The women in the focus group discussion were still in the middle of their treatment, some at the beginning and others at the end. Some women only had a mastectomy, while others went through the whole range of treatment including chemotherapy, radiation therapy and hormone therapy.

All interviews were conducted in Dutch and the average length of the interview was 2 hours. The age of the participants ranges from 40 – 70 years. Most of them were married, only a few were single. Most of them had children.

After the first round of interviews and having finished my first draft of the thesis, I asked one woman who also underwent treatment to read the thesis and give her comments. Those comments were also included. All informants were offered a copy of the final report and were invited to comment on the study results.

Critical notes

I still think that my choice to do a study on this topic was a good one. However, I realise that my approach is based on issues that bothered me while coping with breast cancer. Therefore it is completely biased and does not necessarily presents themes of concern of other women.

During the first interview, I realised that being a companion in distress, looking at the topic from an emic point of view, also made it more difficult to be a researcher. I felt a need to share my own experiences with the interviewee. Once this became clear to me, I paid extra attention to this in the following interviews.
Being able to record all the interviews helped a lot. It was also facilitated by the fact that the women were very open in sharing all their thoughts and feelings with me. I did not have to ask many questions. They were the ones who talked.

I realise that the number of interviewed women is small. However, it should be noted that the selection of the women was randomly done. The only thing they all had in common, besides breast cancer, was their willingness to participate. None of them was a friend, except for my friend who read my thesis after the study was carried out. Maybe their willingness to participate was based on their coping relatively well with their illness. It is possible that especially those who find it difficult to talk about their experiences and have more problems with coping did not want to participate. When I was asking women, I had one woman who refused because it was too emotional for her.
FINDINGS AND INTERPRETATION

Introduction

Breast cancer is the most common kind of cancer for women in the Netherlands. In the Netherlands, there are around 70,000 women with breast cancer. There are 10,000 new cases a year. Yearly three thousand five hundred women die of breast cancer. The five-year survival rate is 76 percent. Most women diagnosed with breast cancer are between 45 – 75 years of age.

There is a certain sequence in the diagnosis and treatment of breast cancer. Once a woman enters the health system after discovering that there is something strange in her breast, a mammogram and ultrasound are done, very often followed by a biopsy of the tissue. All need to be evaluated or examined. This takes a couple of days or a week. When the results are known, the woman will hear what kind of treatment is necessary. If the tissue is malignant, an operation will follow in almost all cases. The removed lump or complete breast will then again be examined to see if all malignant tissue is removed. Depending on those results, additional treatment will be advised (chemotherapy, radiotherapy or hormone therapy). Generally, this whole process takes at least a month.

Dealing with cancer

The confrontation with a serious disease, and especially cancer, has a great effect on the individual. Besides coping with the physical effects of the disease, one also has to cope with the psychological effects. Everything considered as a matter of course is no longer accepted unquestioningly. This influences the life of a person, the social network and other activities. Generally, the confrontation with cancer triggers feelings of fear, loneliness and dependency. Feelings of fear might be linked to the future, death or treatment. Loneliness might be an issue because others do not feel what the person feels. Others might not
understand the loss of confidence in one’s body and not knowing what to expect of the future.
Very often a healthy person does not realise in how far our personality and well being depends on factors outside ourselves, how much we depend on others, work or society. Suddenly a person is dependent on others, the health care system and the health professionals. This dependency will be there for a long time because of the very frequent contacts in the first period and afterwards because of the yearly check-ups.

The women I interviewed experienced the following when confronted with breast cancer. Receiving the message that they had breast cancer was devastating. It turned their world upside down.

“One black hole”

“*I never thought I would get cancer. If somebody would get it, it would be my husband; he has been struggling with cancer his whole life. When the doctor told me I had breast cancer, I cried for two hours. Then I decided I had to tell people, because when telling it to people it becomes reality. The more often I told someone, the more I realised I had breast cancer. Now I realise that it must have been horrible for the people I told. I told it more to myself than to anybody else*”

“I never thought I would get cancer, I thought of many other diseases, but cancer, no…”

Another woman told me:

“I had problems with my breasts for a long time, mastopathy. One day I felt something and they did a biopsy again. I thought, like always, that it would be OK, but when I came for the results, the doctor told me that it was 50/50. I panicked and called my husband”.

The oncology nurse told me:

“I do not see many women before the operation. The ones I see are the ones who have many questions and fears. Their main concern is the fact that they have cancer“.
Most of the women I spoke to discovered breast cancer themselves. They felt or saw something strange at their breast. Others had husbands who saw it first. Only one woman found out through the yearly check-up, when a mammogram was done. Women reacted very differently in the first weeks. Some thought that everything would be alright, it could not be malignant. Others already saw their lives ending. All were anxious and afraid and wanted to know what was going to happen. Some were told that they had to wait a couple of weeks for the operation. This was contributing to the anxiety.

“When they told me that I had to wait for at least two weeks, I really got scared. I had the feeling that the tumour was growing very fast”

“They told me that waiting was not a big problem, because it was a very slow process, but I had the feeling it could enter into my lymph nodes any moment, that we had to prevent”

Not all women felt this way and one was actually quite happy to postpone the operation. This woman told me:

“I asked him if I had to postpone my holidays, he said: if it is wrong now it will be wrong in four weeks time, you take your holidays and so we had our holidays, really nice “

Especially in the beginning, many women kept a diary to write down their experiences. The following quote is one out of a diary

“It is strange to think that I might not be there anymore next year, it is strange to think I might not get better. It is good that my brother is coming tomorrow, it might be the last time he sees me in good health and I have to cry each time someone is leaving. Nothing will be the same anymore”

Most of the women I spoke to had a mastectomy and some had lymph node removal. Only two women had a lumpectomy. They all had to wait a couple of days for the test results of the removed tissue. One had to wait for three weeks until the results were known. This waiting was experienced as horrible.
“I was operated on Monday and on Wednesday the surgeon came to collect me from the room. I thought: “Oh my God, they have the results, it is wrong, he is coming to collect me”. But it was perfect. He did not want to tell me in the room, because there were other women who were told that everything was wrong”.

“You don’t sleep, I had a lot of pain, your death penalty. You have to wait for the results, I was already organising my own funeral and thought I am going to make a tape for my kids to tell them what I think is important in life. That week was really difficult”.

“I did not think a lot the first days, I felt a kind of euphoric, was convinced that the tumour was removed, it took more than three weeks to get the result that was not good. Those first days were fine, I knew I had to wait, but the longer it took, the more anxious I got. I knew it was not OK. After two weeks I started to get an infection and at that time it was horrible, it felt like the cancer was spreading throughout my body”

At the same time, there were also the positive experiences of some women during first weeks. They felt overwhelmed by all the attention they received.

“ It was very nice, everybody was really nice, I had a room by myself. I received a lot of flowers, cards, and attention. It was so much that the nurses said that maybe we should put the flowers somewhere else. I said: No, I need this, I need it all, I can’t have enough”

“In comparison with all the other women on the ward, I felt like a queen”

“I had so many flowers, it was too much, it really helped. The idea that so many people think of you, helps”

Non of the women forgot the moment when they heard the news. All women had their moment of despair, some very quickly after the diagnosis, others at a later stage. They all felt that their world collapsed. The waiting for the operation and the test results was experienced as draining by some, while one was relieved that she could postpone the operation and go on holidays.
Although all women had a very difficult time, they also had very positive memories of that period, because of the attention and the support they received.

**Support**

When asked how the women would describe their social network, those of whom they felt were most important for them during their illness, the answers varied a lot.

"My family is the most important, not only my husband and children, but especially my sisters. After that good friends, especially those living close, neighbours, in the street, we are kind of old fashioned with neighbours”

"My direct family, husband and children, sisters and parents, no direct friends, but support from people from my work. I received a lot of support from my husband and children. I thought that I would get more support from my own family, but that was a disappointment. Maybe because it was too much a confrontation for them and they were not able to handle that. I think that I received a lot of support of people I did not expect it from, from people I work with”

“ My husband, colleagues and family of my husband. I did not have any support of my own family”

"I had a lot of support from my family and friends, they all were there, all in their own way. I felt really protected and cared for. Also my colleagues at work and other people a bit further away were very supportive. Everybody was really concerned. Actually, there was only one very good friend, who, for whatever reason, completely abandoned me. I still don’t know why”.

Generally, the women received support from their families. Some women were single and received support from their family/friends. Some of them felt disappointed though about some people like the quotes above already mentioned. Some of them also felt that the period after the treatment was much more difficult.
Three women told me:

“It is interesting when you have a scary disease, but as soon as they hear it is going better, it is over. You have to cope with it yourself, but I must say my husband really helped me, not my family or a good friend. I also think it is still a taboo, people do not know how to handle it”

“During the time you are busy with your therapies, everybody is extremely concerned. Once that is over, you are by yourself, you have to deal with it. Everybody thinks you are better, you get back your hair, look healthier and things are back to normal, but for yourself it is not back to normal, you have to pick up your life again. It is funny, during the treatment period, I hardly felt lonely, it was only after the treatment that this happened”.

“In the beginning it was fine. After that, I at least needed half a year to physically recuperate, my husband wanted to talk about what happened to us, I was not busy with that at all, I was just trying to get my strength back. So, we were not really able to communicate. We were on different tracks. I remember that I thought, when one friend of mine told me that I had to be prepared that our marriage would suffer, that this would not happen to us, now I was wrong. I never had the feeling that this happened because I now missed one breast, no”

It is clear that, for various reasons, this period after the treatment was experienced as very difficult. It seemed that it was especially the period after the treatment that women found that the support they got is not enough. The people around them did not really understand what was going on. For them, the person was better, but for the woman herself the healing process just started. Some women started working again very soon after they went through the operation. They found that their colleagues were very supportive. Other women needed more time to restart their work again, especially where additional treatment, chemotherapy, had been necessary.
Body Image

After the initial examination through biopsy, there sometimes is a moment of choice. Some women can choose to have a lumpectomy, others know that a mastectomy is needed. Some women do not know if they will have a lumpectomy or mastectomy before they go to the operation theatre. They will only find out after the operation. The women I interviewed had the following experiences. 

"I said, I am absolutely sure, I want to have a mastectomy"

"When the surgeon told me that he first would do a lumpectomy, I was relieved. I did not have to loose my breast. By the time I had to go through a mastectomy, I was so fed up with my breast, I knew so well why I wanted to get rid of that thing. It wasn’t my breast anymore anyway. Because of the infection, it was red, only getting bigger and very painful. I wanted to get rid of it. That feeling was so strong”

“I did not know before the operation, it was sink or swim. When I woke up, I did not know what happened. You do not feel anything because of the bandages. They told me straightaway (m)”

The oncology nurse told me:

“Actually, there are two groups of women: one who says to be happy that they loose a breast, because they get rid of the cancer and the other group of women who start to talk about reconstruction straightaway. I believe that the first group is larger than the latter. For most women, getting rid of the cancer is most important”

How did women feel about themselves directly after the operation?

“I remember I was relieved. I had so many problems with my breast after that infection. I was so happy that it was removed. When I saw myself in the mirror, it looked weird. I prepared myself for a shock, but it was not that bad (m)”

3 m stands for mastectomy, l for lumpectomy
“Most shocking was that there was a long wound, from the middle till right down under your armpit, I did not know it would be so big, I knew the breast would be removed, but the wound was ugly”

“I was shocked, not that the breast was removed, but that the wound was so big, I thought because I have small breasts that this would be smaller”

Apparently, women were not prepared for this. They prepared themselves for the amputation of the breast but did not realise that the surgery would leave such a big wound.

Nurses in the hospital guided all interviewed women when confronted with the view of the amputation. Most of them were asked when they wanted to see the wound. It was strongly suggested that the partner or one of the family members should be there, when they had their first look. It is extremely important that the partner responds in the right way. The oncology nurse felt that the mastectomy was not a problem for the partner.

“Often the partner does not find it a problem, something like: it is a pity, but you are not changing because of that, it is not important”

There can be a clear difference between the reaction of women directly after the operation and later. The first four quotes are from women who were operated more than three years ago.

“I never felt less a woman. I now look this way and that is as good as before (m)”

“I am used to it, although I think it is still a mutilation. No, I never had any problems with it. Nowadays you have really nice prostheses (m)”

“I thought: this is needed, okay, finished, and with the prosthesis, you do not see it. I learnt to accept this. maybe I am a very positive person (m)”.

“I am fine, it does not really bother me, it looks healthy and I remember that I could feel my heart beating against my ribs, in a way that was a new feeling”
Other women I interviewed were still in the middle of their treatment and the experience was still fresh so to say:

"I feel less sexy, I try to imagine. I do not have a partner at this moment, but I think I have a picture in my head, that I am less attractive for a man, but I know this comes from between my ears (l)"

"I avoid looking in the mirror a bit, the mirror is also hanging a little bit higher. No, I can’t get used to it. Not that it really keeps me awake, but I miss something. Even though it was a breast saving operation, I miss something. You become very self conscious (l)"

The following findings come from another study carried out among women with breast cancer. (Brederode and Floor, 1977)

"I never looked in the mirror. It took a long time before I was able to look at myself. I am damaged"

"That ugly body, it is flat, you are just like a boy, you can see the ribs, you have become very ugly"

"Never had any problem with it, I would never show my mother, because she gave birth to a healthy child. You should not look at it aesthetically"

"The mutilation was the most important thing, maybe not even for myself, but for my husband"

"Horrible, till today I can not get used to it. It looks horrible and it gives me a sad feeling. I can not really express it in words, but I feel horrible"

I asked the lady of the prosthesis shop about this as well, because she sees all these women for a prosthesis after they had a mastectomy. She said:

"There are indeed a number of women who feel less feminine, but there is also a big group of women who feel not like that at all. What I notice is that women who were very fond of their breasts, show off, have more problems coping with this than women who see their breasts differently"
She also commented:

"Women who already went through some trauma before, cope better than women for whom this is their first traumatic experience. There is a percentage of women who still finds it difficult to cope with after 15 years. Whereas I also have a group of women of whom I think: Ok, they are themselves again when they come to me after a year”

It seems that women need time to get used to the fact that they are missing a breast. They have to cope with the fact that they have cancer, they have to go through all kinds of therapies and last but not least they have to cope with their mastectomy.

It is clear that some women cope better than others do. In my research, time was influencing factor. It is not clear to me when the women, quoted under other source, were interviewed.

There were several comments about the fact that the women still had one breast.

"When thinking about loosing my breast, I thought they better take off both, then I will be symmetric again, but afterwards I realised that was wrong. I am happy I still have the other one and it doesn’t matter that you are asymmetric”

"I still have many problems with my other breast, because of the mastopathy and I thought that I also wanted my other breast removed, but that is too big a step”

"I am so happy I still have my other breast, only the thought that I have to miss that one as well, no…”

"Having one back is enough, two backs…. “

In relation to body image, several women made comments about the prosthesis and the appearance to the outside world.
“I will always wear a prosthesis, not so much because of aesthetic reasons, but more that I want people to see me before they see I had breast cancer”.

“For the outside you do not see anything but I have the feeling that everybody looks at my breasts, funny isn’t it. I am very self conscious about it”

“It is strange, but when I hug a man, I always think he will feel I am missing a breast. I do not think about this when hugging a kid, and I also know that this man probably feels nothing”.

“I went to the sauna, I was really scared, but my friends convinced me to come along. It was fine; people were nice to me, even nicer than normal. I was afraid to shock other people, that was my fear, but it went fine”

“I do not think I am going to have a reconstruction, maybe I will stop using a prosthesis. It is actually ridiculous. An amputation of an arm or leg is accepted, but a woman with one breast has to be camouflaged”

Just last month a book was published in which eight young women tell their breast cancer stories (Vonkeman, 2001). One of them said the following

“I can look at it without problems, and I do not find it difficult to show others, depending on the mood I am in and the situation. At my work we have separate changing rooms (she is a sport-instructor) and I am happy with that, otherwise each time I have to explain it to people, that is tiresome”.

Appearance to the outside world is important in our society. Having only one breast is something you can hide by wearing a prosthesis. All of them realised that they put on a masquerade for the outside world, but decided to do so because they felt more at ease like that than having to explain it all the time.

Gaining weight because of treatment or just getting into a different stage in life is sometimes a bigger problem.
“I feel happy, the only thing that troubles me is my belly, I gained weight, I do not like that”

“I honestly must say, I am getting a belly now, not nice. This I find more troublesome than the fact that I lost my breast 22 years ago. Nobody saw anything of that, only my husband or close relatives, that did not matter”

Sexuality

The fact that women are happy that they still have one breast is related to their sexual relationships with their partners. They mentioned this:

“I never felt that my husband saw me differently. I still feel everything, as long as you have one breast. I want to keep that feeling….as long as I have one breast”.

“When making love, I still have a feeling in that breast and if I would not have that any more... there is a tickling”

“When you touch the nipple, it give a certain feeling, nice. Now that you have lost it on one side, there is still one side left, but to me it seems that that side is also a little less sensitive, that is a pity. For the rest it did not change, it is the same, nice, fine.. “.

“I like it when my partner touches my breast. It feels good and I do not miss the other one. The fact that I now have one breast did not change the feelings when having sex. In the beginning, after the operation, it felt awkward, but I got used to that very quickly”

“I am already it little older, but when I am in bed with my husband, it is very nice to lay close to each other. I am very happy I still have one breast. Some people ask me why do you not remove the other one as well, I can not imagine that”.

The removal of one breast and sexuality is complicated. The women from the quotes above seem to cope well. Others may not cope so well. It is known that women are feeling less attractive.
There were remarks about the fact that women found it important that men still found them attractive. I personally believe this counts for many women, with or without breast cancer. Like most women, it was important for all women interviewed to be seen as an attractive woman. Having their partners tell them that they are attractive was assuring, but it was very nice if other people also found them attractive. This also helped to get their self-esteem back.

According to the oncology nurse

“It is often the woman herself who has problems with it. The partner hardly finds it a problem. There was a woman, who found it extremely difficult to have sex with her husband. She was very resistant. They talk about it. It is very often a victory for the woman herself to allow the husband to see and touch her”

For women who did not have a relationship at the moment they got breast cancer and had undergone a mastectomy, this was a real worry. It also was only one of the things they worried about.

“Just after the operation I was not even thinking about a sexual relationship with a man, there were so many other worries. It was only after about a year that it happened. It was probably the first thing I told him. I had not seen him for a long time. The first time I went to bed with him, I was nervous and felt very vulnerable. He was very nice and sweet and it was fine. After a couple of times, I almost forgot that I only had one breast. It is complicated, but I managed (m)”

“It is a kind of mourning process. I could have started something, but I thought: No, no, I first have to recover myself. I think I need time (!)”

The oncology nurse said the following when I asked her if this was something women mentioned.

“Yes, this is something which comes up, especially with young women who are not in any relationship at that moment. They ask themselves how they are going to cope when they meet somebody. It is a step you have to take yourself when you meet somebody, you have to tell that you miss a breast, that is difficult”
Process of change

When asked, all women said they had changed because of their illness. As already mentioned before, women went through a mixture of positive and negative experiences. Some made major changes in their lives, others felt they changed in a more subtle way and on a different level.

“When I was going through all the therapies, I did things I always wanted to do, but never had the time for, so I sculptures, made painting, played the saxophone. This was really nice, it helped, was therapeutic. I read a lot before, but at that time I found it really difficult to concentrate. I realised that I did not do anything with my hands for a long time, things I used to enjoy a lot in the past, I think I am much better in balance now, with the things I do, than I was in years.”

“I see the time given to me as a kind of present. I do things I never had time for, you come in touch with a part of you, a part you never had time for”.

“The process of change did develop over the years, also because of my illness and the tumours I had afterwards. It went very slowly. I thought that I wanted to do things I also wanted to do before it was too late, so that is what I do, I always wanted to go skiing and never did, now I go twice a year, it is fun. I also am less bothered by what other people think, take life as it is, and do things that are good for me. I am much more conscious of things, do not postpone them, and do them now before it is too late. I have changed, am more myself, I do not know if this is only because of the cancer, you learn and change because of what you do and what you experience”

“My work was very important for me in the last years. I worked very hard. Now I find other things much more important, friends, family and hobbies. I realised that I was far too much focused on my work, which I still like but now it has a completely different place in my life. I hardly think about the future anymore, I live much more by the day. I do plan things, but not much further than the next holidays. I am alive now and live by the day, that I really like”.

40
“What I really found difficult to accept was that the matter of course of life is gone. The fact that this can happen to you just like that and that you can not rely on your body anymore, that I found very difficult to accept. You have no complaints and then this happens to you. I lost the confidence in myself, my self-esteem was gone, it took me quite a while to regain that again, that you know who you are, that you are healthy, that I found difficult. Besides that, people who are very close to you also get hurt. They have to loosen the bond with you a bit to protect themselves against the pain, but you at the same time, do not want that, you want to keep them as close as possible. In the first year after the operation, I had to struggle to get that in balance again. You have to think about a lot of life matters. These have to get a new place or the same place in your life as before. This I really found difficult, but also valuable. It brought me more good than bad”.

“I became nicer, more beautiful, softer for myself and therefore also for other people”

“I let things go much easier, if I have to be worried about all the things I see around. Yes, I became much more relaxed.”

“I do not think I changed so much, but I do enjoy life more, daily life, I think less about the future, I enjoy things more and intense”

The lady of the shop told me the following

“ What I notice is that, especially the younger women are going to do things they always planned to do, but never did so far, things they are good at, starting businesses, things important for them. I really admire that, this fighter spirit of those young women. I also see women separate from their husbands, because they changed, grew and the man of before is not the right one anymore”.

The oncology nurse said

“I think that the self image of women does change, more because they have cancer, than because of the mastectomy. They experience life differently; it is more about where do I put my energy in. This is not determined by loosing a breast but because of having cancer”
All women I interviewed told me they did change. This was also the impression of the oncology nurse and the lady of the prosthesis shop. All of them felt that they changed in a good way. This is interesting because this positive change does not always correspond with the change in body image. Apparently, these are two different things. Coping with cancer and surviving gives a positive change although loosing a breast might be difficult.

**Fear for the future**

All women are afraid that it might come back in the other breast. It is a daily reality.

“I am much more alert. Whenever I find something, I call the doctor. My posture changes, I become really cramped”

“Especially in the first years after the therapies, I did not have a lot of confidence in the future. Every time I had to go for check-up, I was prepared to hear the bad news. Now a couple of years later, this is changing again. I do not think a lot about the future, good as well as bad things. I will see. This is strange, because all the people around you think that you are better and completely healthy again. They do not understand well that I can not think like that anymore, it is a very lonely process. Only people who went through the same understand and know how that feels”.

“It has been a long process, I have been afraid for a long time, every pain I felt, I thought… I learnt how to handle that. I now know what kinds of therapies are available, I am getting older and tumours do not grow that fast. I am getting tamoxifin that helps. It was especially in the first years after the mastectomy that I was very restless. After the radiation therapy, it took me two years to be able to continue normally. Now I am okay but mentally tired more quickly. Every time the feeling that you have to start all over again, that is horrible. But one way or the other you keep faith in your body and maybe in medical knowledge. The confidence comes back. You only believe you are dying when you can not do anything anymore”

“ I live with the idea that it will come back, that definitely changed”
Contacts with health professionals

During the whole period of diagnosis and treatment, all women had weekly, sometimes daily, contact with their surgeons and oncologists. It is clear that all the women went through a very complicated process of dealing with cancer, facing death, coping with the mastectomy in a network of partners, family, friends and health professionals, who were playing in central role in this process.

“My surgeon was a fine man, not a talker, but I also prefer a good technician. I was very much in control of everything, I was directing the events, what and when something should be done. I felt very respected as a person. For me that was very important”.

“I ask everything. Whatever keeps me occupied, I ask. I get the information I need. I think that I do not get a lot of guidance, but that I guide myself. I go for check-up every six months but whatever they do depends on what I tell them, except of course when my blood is not good.”

“I had the feeling I was very much in control of everything, although the surgeon was a real surgeon. He took the time to explain everything. Before I would go to the appointment, I would write up many questions and ask them. I also taped all the conversations with the surgeon. I remember he did not like this so much, but as he said if this helps you, I have to agree. So it happened. He was not a very good communicator, but he tried. He was very sweet and caring, that I felt very strongly and I think he is good in what he was doing that also helps, I trusted him. He was completely different from my oncologist. She was very good in listening. She was very clear in what was needed, but would take all the time to discuss what was worrying me, or discuss different options. My surgeon also did his best, but I could see in his posture during the consultation that there was a clear limit to his openness. This I did not mind, I got what I wanted, all the information I needed and I trusted him. I felt very much respected as a woman and I could feel he felt for me”
“I did not know anything, the surgeon did not tell me anything before the operation. It was because my husband was pushing that just before the operation, I saw the doctor and he explained some things. Nobody told me that I could get problems with my arm after the operation, I did not know if they were going to remove my whole breast, nothing, I was very disappointed in that. I also asked for a second opinion in another hospital, but that was even worse, they said that I probably already had metastases in my lymph nodes. Nobody told me that I had to stop with the medicine I was taking for the mastopathy. The doctor in the second hospital told me to stop. It was bad. Only the oncology nurse, she really was nice and explained a lot. The doctors did not have time to explain anything, that was bad”.

All women experienced these relationships with the health professionals in their own way. The first three women felt very supported by them, the last woman was very disappointed and did not feel supported. It was an extra burden. It is very clear that the first three women were very much in control of what happened to them, while the last woman did not get any information about her treatment. The appreciation for the oncology nurse should be mentioned.

Prosthesis and Reconstruction

About 15 percent of the women who had a mastectomy have a reconstruction afterwards, either directly after the mastectomy or much later. This percentage is low in comparison with other countries (e.g. in the United States of America 33 percent of women have a reconstruction).

Dealing with loosing a breast is a very personal matter. In the Netherlands, women usually are wearing a prosthesis. Most of the women continue doing so for the rest of their lives. Research also concluded that the majority of men (80%) are completely used to the prosthesis, the other 13% are reasonably used to it and the remaining 7% a bit or not (Bergman and v. Dam, 1981). Looking at body image, femininity and self-esteem, the same research showed that the majority of women (70%) feel feminine and 88% mentioned that they are completely used to it.
Interesting enough, and this might be different than when having other plastic surgery done, research shows that significant others have hardly any influence on the decision to do reconstruction of the breast. As already mentioned only 15 percent decide to do a reconstruction. In comparison with other countries, this is very low.

Reasons for doing a reconstruction are diverse. Some women do it because of practical reasons, as if they want to wear loose and open shirts, while others want to save their relationships. Some women do feel incomplete, less feminine after the mastectomy and wearing a prosthesis does not change this feeling. Although women might mention the above arguments, the underlying feeling of distancing from the disease through a reconstruction might be the main reason.

According to dr. Rutgers (special edition of the Mammazone), after the reconstruction, 70 percent of the women are content with the result, 20 percent find it more or less OK and for 10 percent of the women the reconstruction fails. This is because there is either an infection or the women have too many other complaints. Not being satisfied with the reconstruction might be another. Worthwhile mentioning is also the fact that the dissatisfaction with the reconstruction is more often seen by women who had a reconstruction at the same time as the mastectomy. Especially these women might expect too much from the reconstruction. They were not confronted with the amputation and this has a direct effect on coping and disappointment with the new breast. Women who decide to do a reconstruction at a later stage have thought about it a lot and realise better that the new breast will never be like the old one.

The women interviewed who had a mastectomy mentioned the troubles they have wearing bikinis and bathing suits in the summer. That is the time women are most confronted with the fact that they have one breast.
Practical reasons were mentioned.

"I always liked my body. I found it difficult that I could not sun bathe topless anymore. Now I still can not do that but I have nice bikinis. I did not really think it was necessary, but now I did the reconstruction, I am very happy. The scar after the mastectomy was really ugly. When I was wearing a prosthesis, I thought everybody saw it. When you bent over everybody could see a small gap, now you see skin. Now at least I can buy a normal bra, a lot cheaper and when I look in the mirror wearing my bra, nobody sees anything. I still think it is a mutilation. When I look in the mirror, I have two completely different breasts, it is ridiculous, but I am still happy I did it. If you want to do a reconstruction you have to be very motivated, you should do it because you, yourself, really want it, not because your partner wants it. It is really painful, it was horrible, much more painful than the mastectomy."

"At this moment (22 years after the mastectomy) I am ready to have a reconstruction. Actually, I am in the process of reconstructing; the other breast needs to be reduced. You have to be ready emotionally. Each time I was ready, something happened and I postponed it again. I always could wear a normal bikini, but the last years my breast starts growing, from B to D cup, the prosthesis constantly needed to be adapted. The breast becomes bigger and heavier and you start to see it in the end. The last time I had problems was six years ago and I thought now I am going to do it. Look, if you want to do a reconstruction you really need to be motivated. There are so many other, more important things happening and it is easy to postpone again. Now that I am in the process of doing it, I am happy about it."

Another woman was not sure yet.

"I do not know yet, sometimes I think I should do it, but when I hear all these stories about the pain and the results, I am sure I never will do it. Actually, I am fine at this moment, I hardly think about it anymore. I also realise that putting on my prosthesis is becoming like brushing your teeth in the morning. I am confronted with it again, when I am going to the beach and have to check if people can not see my prosthesis. In the end, this might be a reason why I would do it. I think I need more time. Maybe when I pass the five years, I might think about it. I also think this all means that it does not really bother me, otherwise I would do it."
One woman was absolutely sure she was not going for reconstruction. 

“I know that I do not want any reconstruction. I said to the doctor: “do you think I want anything new there, you do not think that I voluntarily go into the hospital again, to get something artificial back, no way. In the beginning I had a very bad experience with my sister, who told me that I had to do it, because I would be whole again, I did not feel like that at all, I always felt whole”

According to the oncology nurse, surgeons hardly discuss reconstruction. If they do, the women are very young. The lady of the breast prosthesis shop mentioned the following:

“I know it is only 15 percent of the women, who decide to have a reconstruction. What I see at this moment, especially among the younger women, is that they say that they do not want to have a reconstruction, another operation, it’s OK. I think that it was different in the past, because of the role breasts play for men. These young women are different; they are stronger, independent. I see older women having more problems, while I think that when older it is less important, but it is the other way around. Older women have more problems with it, feeling less feminine. I think it has nothing to do with femininity, that is in your head and not in your breasts. Younger women get their identity from other things, jobs or profession.

She also commented

“You do a reconstruction because you want to do it yourself. The people around you have nothing to do with that. I noticed that the longer things go well, the more you want to get back. This includes breasts. First, you are busy with surviving and accepting, and when things go well, you want to get your breasts back. That is why I thought, a reconstruction would only be done by young women, but I discovered that there are far more older women doing it”

Again, there is a variety in what women think about reconstruction. The first two women did reconstruction after a quite a long time. They both say that one has to be absolutely sure about wanting it and not because other people push the woman.
The lady of the prosthesis shop also confirms this. Both women who had reconstruction done were neither extremely young nor old (43 and 52).

I

Involvement in an organisation

Since 1979, there is a special patient association for women with breast cancer, the Landelijk Contactorgaan Begeleiding Borstkankerpatiënten (LCBB). Volunteers mainly run it. These women, spread over the whole country, are supporting women with breast cancer. The association offers several services, such as giving information, publishing a three-monthly magazine (the Mammazone), meetings on specific topics, advice about prostheses and talks with other women facing the same problems.

The organisation is active in the Netherlands but also internationally through connections with the European breast cancer organisation. It has several links with all the different hospitals and volunteers are working together with the oncology nurses. The women I interviewed all were aware of the existence of the association. When asked if they were actively seeking help from women in this association, they told me the following:

"In the beginning I did not want to have a lot of contact with other women who had breast cancer. I visited somebody later. Now I am a member of the board of the Contact Bureau for Breast cancer. When I got sick, I read a lot of information and I was very disappointed and angry. A lot of the information was about how to prevent it. It was almost as if you had to blame yourself for getting it. I find it important to contribute to this, to give support to women. I was able to find my information, but I have a very strong feeling that you have to search for information yourself. If you are not very verbal, what kind of information are people offering you, unasked?"

"I visited some meetings, and I am a member of the mastopathy club. For the rest, I do not participate in anything. In the beginning, I needed it but now..."
"No, I am not, that was too much for me, I talk with my family and friends. Talking with other women with breast cancer would have been too constraining for me, I did not want that. I could cope very well by myself and the confrontation with other people’s misery would have been too much. If you want to cope you have to talk with people, not necessarily other women with breast cancer, but friends”

“I am not involved in any organisation yet. I also did not contact any organisation while I was sick, maybe I was lucky I knew some friends of mine who went through the same and had many family members and friends around me with whom I could talk. I am a health professional myself and therefore know quite a bit about cancer. I also was afraid that when I would go to these self-help groups I would fall into the trap of becoming a therapist myself. At this moment I do share my experiences with other women, who are faced with breast cancer. I realise that it is important to do this. I think that in the future I will volunteer to do something for the breast cancer organisation”.

As written before, yearly +/- 10.000 new women are faced with breast cancer. The association has 5.000 members. Many women are not seeking any help of this organisation. They either do not know of its existence or find help in other ways, through friends or acquaintances.

Summary

Ten women were interviewed. Their struggle with cancer started when they heard they had breast cancer. The confrontation with this disease and possibly with death was devastating. Then they had to go through a diversity of treatments, all of them with their own problems. Some were experiencing a lot of pain.

All were faced with the fact that their body changed because of either the lumpectomy or the mastectomy. Remarkable was the fact that some of them were very shocked by the size of the wound and not so much by the amputation of their breast. Apparently, they prepared themselves better for that.
They needed time to get used to their new body. Some were able to pick up their lives quickly and others needed more time. Although some of them now only had one breast, their feelings of femininity, attractiveness and sexuality were still there. I did not see a lot of difference in coping with the changed body between women who had a lumpectomy and women who had a mastectomy.

They all valued the support they got from the people around them. This was important for them, although some told us that the period after the treatment was far more difficult and complicated. This was not always realised by the people around them. They all said that they changed because of what happened to them in a positive way, enjoying life more, less troubled with what is happening around them and choosing for themselves.

The interaction with health professionals was satisfactory for most of the women. One woman felt that the support given was very poor. While some decided to have a reconstruction done, others continue to wear prostheses.

Coping with breast cancer is a very personal matter. The variety in quotes in the selected topics demonstrates that women, all coming from the same society, experience the process in their own way and deal with it in their own way. In the course of the disease, they are faced with many problems, but they all seem to cope well.

I realise that the number of women I interviewed was small. I do not know about women who did not cope very well, maybe it is this group of women whose voice we will never hear because they suffer in silence.
"Who owns the breast" is the title of this thesis. This title was chosen because I felt that there are many controversies around this phenomenon: women, breasts and related to that breast cancer.

It is interesting to see that many people think they know something about the cancer prone person, what women do when faced with breast cancer, what they feel and how they cope. I am aware of the fact that by interviewing only a few women, I will not be able to prove anything. This was also not the aim of the study. I looked at how women coped with breast cancer. It might be obvious after reading the findings that all women cope in their own way, diverse as it might be.

I will look at the topic in the view of anthropology of emotions, because I believe feelings and emotions have a central place in the whole process. I agree with Scheper-Hughes and Lock (1987) when they state that insofar emotions entail both feelings and cognitive orientations, public morality, and cultural ideology, they provide the missing link capable of bridging mind and body, the self, the social body and the body politic. Emotions trigger the transformation of knowledge into human understanding and bring intensity to human action or experience. Emotions affect the way a woman perceives what happens to her and in the end determine how a woman copes with it. Emotions might help a woman to get through a very traumatic event, in this case breast cancer.

I also agree with Moore (1994), when she mentions in her book about difference, that each individual has a personal history. It is at the intersection of this history and the collective situation, discourse or identities that the problematic relationship between structure and praxis and between the social and individual resides. It is very difficult to come up with general conclusions about the experiences women go through when faced with breast cancer. This depends on so many characteristics of the women themselves and influencing factors in their environment.
Women and their bodies

In modern society the body has become increasingly important and is increasingly central to a person’s sense of self-esteem (Shilling, 1993). Illness, in this case breast cancer, is influencing the way women perceive their bodies, even more when an amputation of a breast is one of the consequences of the treatment. Derogatis (1980) tells us that a disfigurement of the body results in distortions in body image and sexual functioning. Although this might be true in general, it is not one of the conclusions I want to draw out of my research.

The women I interviewed did not experience this in this way. The women who were still in the middle of their treatment did have problems with their new bodies, had to get used to it (I do not know how they will adapt). Those who already finished their treatments all accepted their bodies and did not feel less a woman. They changed because they had cancer but did not feel less feminine. Some of them were actually very sure that they wanted to have their breast removed to be sure that the cancer was gone. Others did not have a choice. They all were happy that they still had one breast and their sexual relationship with their partners did not change because of that. What some of them found more difficult is that they could not trust their bodies anymore and that they had to live with the fear of a recurrence of the cancer. The lady of the prostheses shop also confirmed this.

What is far more interesting is how the people around them handled this and how important this was for the women. All of them were wearing prostheses, because they felt more comfortable with it and because they wanted to be seen as normal and not having to explain what happened to them. They wanted to be seen as whole persons. They themselves accepted their bodies the way they were, people around them might have found it more difficult.
Kelly and Field (1996) state that chronic illness, in this case breast cancer, changes the self and identity and that people around the person only see that when external signs are shown. When people know that someone had a mastectomy, they start their own line of thinking/feeling about this, based on what their own perceptions of their bodies. Those do not necessarily correspond with what the patient thinks. The example of the sister of one of the patients pushing for a reconstruction is a good example. It also might be that the women themselves thought that the people in their surroundings would think this way. They also are part of the same culture and have internalised the way of thinking about a woman’s body as much as anybody else.

It is said that in our society breasts have special value and are central to women and men. Individual women will cope in their own way. This is very much influenced by their feelings on which they base their identity and self-esteem and how they experience their own bodies. When one judges the identity of women on their attractiveness, and of their femininity to their breasts and bodies, then the women have real problems.

In all the in-depth interviews I carried out, women told me that they did not feel less feminine, less a woman than before and neither did their partners feel that way. How does this then correspond with the general stereotyping of a woman with breast cancer, as a deformed, less sexually attractive and feminine woman? It might be true that our society has an idea about what is feminine, attractive or the “ideal” woman. How many women answer to these ideas anyway? Does the same not count for too small/tall or thin/fat? The women made several remarks about their gaining weight and some stated that this was more troublesome for them than having only one breast. I think this has to do with the fact that this might be something they think they can control. Being one-breasted was something they had to accept and was easier to hide for the outside world.
So, what about being asymmetric? In our society, women should have two breasts. On individual level, women, although they did not choose it, were happy that they still have one breast. They adapted to their new situation and valued what they still had, be it asymmetric. The problem though is that women with breast cancer, and because of that one-breasted, have to cope with this stereotyping and stigmatisation. Some of them will do it by being “provocative” by not wearing any prosthesis. Others hide it because they do not want to be seen as a woman with breast cancer, yet another will have a reconstruction done. Does this really matter, as long as a woman feels she is doing the right thing, the thing that fits her best? For the women interviewed the real important issue was actually dealing with the cancer, the confrontation with death and the adjustment to a new way of living in this world.

It is interesting to see the clear difference between women who recently had a mastectomy and those who had one a while ago. This indicates that what women need is time to adjust to their new self. Some will find this very hard and others will do it easier. The women in the interviews were thinking much more about how to survive cancer than anything else. I do not want to say that they did not suffer pain and sorrow when loosing a breast. That might be obvious. Loosing a body part is never pleasant, but for many, it was not the most important thing. White Stewart (1998) writes that women judge their own body based on other people’s judgement. In the first period, after the women receive the news, go through mastectomy and other treatment, this might be true. But is the fact that women have cancer not more influential than having one breast? Do not all people faced with cancer and death share the same experience?

How did the women cope?

The married women told me their family, and not only their husband, but also children and sisters were extremely important throughout the period. The single women told me that their family and friends were very important.
Kravdal (2001) argues that marital status has a positive effect on cancer survival. In my research, I did not find that so clearly, but of course my sample was small and the study not quantitative. I do not think that being married per se guarantees better coping with the disease. The married women I interviewed all mentioned that their husbands were very important. One of them also told me that they, she and her husband, went through a very difficult period after the treatment was over and that they were on different tracks. Actually most of them, with or without partner, mentioned that the period after the treatment was more difficult than the first period. I do not argue against the fact that a partner\(^4\) is important in this whole process, but I see the partner more as one of the people of a whole support system. One can even argue that having a partner in some cases might be constraining as well. In the whole process, a partner is very often the first person who gives support, is always around and shares all the ups and downs during the whole period. He is the central person in a social network. All things are discussed with him, but he is also only one person with his own ideas and beliefs. Sometimes it might be better to have more people around to get the support from, to discuss your problems and to seek help from. This puts a lesser burden on one person and therefore it might be better in the long run.

Everybody has to agree with the fact that having a close friend, family member or partner going through cancer is troublesome and difficult to cope with. Sharing it with as many people close to you very often makes it easier. The women all had a solid social network, but still, having to cope with the people around them was not always easy and sometimes created additional problems. An interesting remark from one of the interviewees was that she felt that her sickness was too much for her family and that they were not able to handle this. Another woman mentioned that a very good friend abandoned her completely.

\(^{4}\) Partner can be both male and female
Kravdal describes marital status in the sense that it reflects the care and support given by family-members, better financial circumstances among the married, and the tendency to avoid risky and unhealthy behaviour because of family responsibilities or social control. This puts the unmarried woman in a very awkward position. Although I agree that in many cases coping well with cancer is facilitated by all the above mentioned, it does not exclude single women from living under the same conditions. It should be interpreted with caution. Are married women better supported by family members, do they live under better financial circumstances and do they avoid risky and unhealthy behaviour more than unmarried women do? The fact that a woman has a partner in a stable relationship also puts obligations on the woman. Especially in the case of cancer, a woman might need time for herself to sort out her emotions and to adapt to her new situation. The quotes in the findings show a diversity of emotions women go through when faced with breast cancer. I think it is correct to conclude that women need time to adapt, they also need a good solid social network that might include a partner.

Derogatis (1980) describes how women who are older and possess a balanced or androgynous gender role definition are less devastated by the disease. I did not find any research looking specifically at age and breast cancer, so I can not comment on that. The only thing I want to mention is the remark of the lady from the prostheses shop. She stated that she was fascinated by the strength of young women because of the ways they cope and the changes they made in their lives. She commented on the fact that young women are different in the sense that they are more independent and stronger and decide more for themselves. She also mentioned that she had the feeling that older women have more problems with the illness than young ones. She felt that this had to do with their gender roles.

The androgynous gender role definition is a completely different matter. Androgynous is described as possessing both male and female characteristics. What does that mean?
What are male and female characteristics? Maybe the Amazons out of the Greek mythology were the women coming closest to this definition. They were mothers and warriors and to help in the latter they cut off their right breast to be able to draw the bow better. As Yalom (1997) remarks in her book, they were not appreciated for that, because the missing breast created a terrifying asymmetry: one breast is retained to nurture female offspring and the other is removed to facilitate violence against men. It is probably true that the Amazons with this deviant behaviour were a real threat to the men in that time who were used to having women as only nurturers of their children and not competitors on the battlefields.

To come back to the present, male characteristics might indicate the fighter’s mentality, having a profession, being independent and having a role in the outside world. We all know that the society, in which we live, sets the framework for our cultural values, norms and rules. We also have to realise that society is changing because of its inhabitants, both female and male. In this changing society, young women play a different role than older women. They have more opportunities to develop themselves and in many ways are less dependent on the traditional female roles. They are ‘potential’ rivals, with or without breasts.

**New persons?**

Many authors stressed the fact that women change because of their illness. Chronic illness changes one’s self-conceptions (Kelly and Field, 1996). An amputation leads to distortions in body image and sexual functioning (Derogatis, 1980; Love, 1995; Couser, 1997). Lorde (1985) tells us that an amputation needed to be internalised into a new feeling of self-esteem, but also that she became a more complete person. Couser (1997) remarks that because of this serious illness, one gets the opportunity to choose the life one wants to lead as opposed to living out the one accumulated over the years. Sontag (1978) talks about stigmatisation and marginalisation of the cancer patient. Murphy (1995) argues that disability should not be seen as social deviancy, neither should a cancer patient be seen like that (Little et al, 1998).
One should look at cancer patients as people in a liminal phase: liminality in the sense of experiencing illness and being in transition.

All women I interviewed told me that they changed. They felt that they became better persons, for themselves and some also nicer for others. Some of them did things for which they never took the time before. They clearly choose for themselves and felt richer, better in balance. They were less bothered by what other people thought about them. They learnt a lot. They themselves felt neither marginalised nor stigmatised. This does not mean that their surrounding people, their social network did not find this. When talking about their sexuality, they said that this did not change a lot in the sense that they still enjoyed it as before. Those who had been sick a while ago were very clear in that they felt whole persons, although their body changed. Those still in the treatment period were insecure about this, did not know yet. I agree with Murphy and Little et al when they state that cancer patients are in a liminal phase, not so much because of the changing social relationships, but more to evaluate their own lives and find a new balance.

Because they chose for themselves, they were less bothered by what other people think about them and in a way were less controlled by their surroundings. However they all were conscious about their appearance to the outside world and decided to wear prostheses or have a reconstruction done. Although they realised that it was a masquerade, they all, for different reasons, adhered to the existing norms of a female body, being two breasted.

Women and their doctors

Most important for the patient is that she can trust the health professional, that she gets clear and extensive information and that she has confidence in the technical skills of the surgeon. There are ample examples of experiences of women where one of the above went wrong. Unnecessary anxieties are created by not getting the right information.
This, maybe unjustified, can also create a feeling of mistrust towards the health professional.

One woman was very disappointed in the support she got from the doctor. She got very little information from the surgeon and was very poorly guided throughout the period, except for the support she received from the nurse. The other women were satisfied about the contacts they had with the health professionals. They felt that, because of the way they were, they got what they wanted. They were in control, directing the contacts, were getting the right information and felt much respected as a person. The fact that they specifically mention this indicates that there was possibly some tension in these contacts or that they were afraid that they would not get it.

There are ample examples in which the contacts with health professionals created many extra anxieties (Vonkeman, 2001; Couser, 1997). Contacts with health professionals are complicated. The interviewed women wanted good technicians, needed to trust them, feel respected and at the same time be able to make decisions. This puts the health professional in a difficult position. Moreover, as all health professionals are also people with their own perceptions and sensitivities, not all are able to do this well.

Surgeons seem to have more problems with this than other medical professionals. As the women tell us: a good technician but not a talker, doing his best but to a certain limit, not telling me anything but only because we pushed he had to explain things. Does this then imply that the surgeons wanted to be in control or does this only indicate that their communication skills were not prefect? I would think it is a bit of both. Possibly, a surgeon tells the patient not all what can be expected because he/she feels it is too much to handle for the patient. This can be interpreted as controlling, paternalistic...Despite what the literature tells us, I did not find clear indications for that in my interviews.
I do think that the contacts with the health professional do create extra stress, purely because they are the ones who have to tell the bad news. They have to tell the women what to do and still the women have to decide for themselves. There are standard protocols for the treatment of breast cancer, but I think we have to realise that subjectivity in the approach of health professionals is a fact. Sometimes this is good, but sometimes this also works in a counterproductive way.

**Breasts, a public good?**

Breast cancer is in the picture. Many women wrote books about their own experiences. On the Internet breast cancer produces many more hits than lung cancer (number one killer among men), not to mention the many more hits you get when searching for breasts and tits in comparison with penis and testicles. I personally do not think this phenomenon is only the result of the fact that breast cancer is the most common type of cancer amongst women. It also has to do that breasts have a special meaning to all of us. It almost seems that breasts are public property. They belong to everybody in this society. It starts already with the importance of breasts for the new born because of the milk they produce and it may well end with the importance of breasts in the sex industry.

In Western culture, breasts are the most visible symbol of femininity. Breasts are seen as sexual objects and whatever women’s magazine you open, you will find something about breasts, be it about size or about cancer. In our culture, in which the ability to control events is important, the confrontation with a life-threatening disease is complicated. We, as a people, are not very good in handling that well. The deformation of a female body because of an illness makes it even more complicated.

Looking at breasts and cancer in the three different bodies, the individual, social and body politics, makes it clear how different and yet linked these bodies are.
While women on an individual level are able to cope and adjust to their new bodies, they also have to find a way to cope with the last two at the same time. They have to cope with what people around them think/feel and on top of that, they are faced with some very strong institutions, such as biomedicine but even more with their own culture, norms and values.

First, they have to cope with breast cancer as an individual. On social level, they have to cope with the stereotyping of how a woman should look, with the stigmatisation as a cancer patient, with the taboos, with their appearance to the outside world. This whole process is very strongly regulated by the existing power and control systems in our society.

As Couser (1997) mentions, women write narratives because they feel they have to share their personal experience with other women, it could well be part of their own healing process. At the same time, it is an attempt to put breast cancer on the political agenda to ask for more attention to the problem. It also is an attempt to criticise the general perceptions on how women cope with the disease, to give a better insight into what women feel themselves and not to follow general ideas about it. For some women the fight against the normative ideas might be the most difficult. To end with one quote of a woman:

"I wonder if there is such a big difference in opinion about body image between women who had a lumpectomy and women who had a mastectomy. I think that others find it more difficult, and also the medical professionals, than the women involved. I have the feeling that the medical world, also looking at the protocols, very much tends to stir towards a lumpectomy. Something like, “as long as we can save the breast”. I think that one of the reasons that it works like that, is because the majority of the surgeons are men, they have a different idea about breasts than women"
CONCLUSIONS

When starting this research and developing the topic guide for my interviews, I wanted to ask so many questions. In most of the interviews the women just talked. It was interesting to see that women almost verbatim could recall conversations they had with others. It might be clear and obvious that women going through breast cancer have a story to tell, have gone through a very traumatising experience and are willing to share this with others. The fact that I was a companion in distress probably contributed to this.

I set out to investigate how women coped with breast cancer and how broader cultural ideas influence this. I discovered that the women I interviewed all coped in their own way. They were able to deal with the fact that they lost a breast and far more important for them, they coped with cancer and the confrontation with death, almost against all odds and given enough time. They were able to adjust to their new bodies and all of them learnt a lot and valued their lives in a different way. They changed because of the experience and it made them richer.

Their fight against breast cancer was not only a private one. They had to cope with what our culture thinks about breasts or physical appearance and this made it more complicated for them, especially because they themselves were sharing the same ideas about it. Each one decided how she wanted to continue her life, be it through having a reconstruction done, wearing a prosthesis or nothing. They chose the path that suited them best and that is also the way it should be, because in the end they are the ones who own the breast.
REFERENCES

Barnhart, M.P.
1994  *Journey Unknown*, Journey Press, USA

Bergman, R.B. and van Dam, F.S.A.M.
1980  *Borstreconstructie; Psychologische en chirurgische aspecten*, thesis

Botter, M.
2001  Toen ik die uitslag te horen kreeg, dacht ik: "dit gaat niet over mij”
       *Libelle*, no.16, pp 56-60

Brederode – Ritter, C. and Floor. M.
1977  *Als je borst wordt afgezet*, Nisso/van Loghum Slaterus

Couser, T.
1997  *Recovering Bodies; illness, disability and life writing*, University of Wisconsin Press

Davis, K.
1995  *Reshaping the female body ; the dilemma of cosmetic surgery*,
       Routledge, London

Derogatis, L.R.
1980  Breast and Gynaecologic Cancers. Their Unique Impact on Body

DiGiacomo, S.M.
       pp.109-137
Durkheim, E.
2000  As in Nepaul A. *Living large, the experience of fat Dutch women*,
       Amma Program Thesis, University of Amsterdam, The Netherlands

Fabian, C. and Warren, A.

Helman, C.G.

Kelly, M.P. and Field, D.
1980  Medical sociology, chronic illness and the body, in *Sociology of

Kravdal, O.
2001  The Impact of marital status on cancer survival, *Social Science and
       Medicine*, no. 52, pp 357-368

Little, M., Jordens, CFC. ,Montgomery, K. and Philipson, B.
1998  Liminality: A major category of the experience of cancer illness,
       *Social Science and Medicine*, vol.47, no.10, pp 1485-1494

Lorde, A.
1985  *Het kankerdagboek*, Feministische Uitgevery Sara, Amsterdam

Love, S.M.
1995  *Het Borstenboek*, Sesam

Manschot, A.
       pp.14-17

Manschot, A.
1996  Met een borst geen vrouw meer? *Opzij*, April, pp.58-63
Martin, E.

Mechanic, D. and Meyer, S.

Meijer-Linstra, F.
2000 *De stilte verbroken, mijn verwerking van borstkanker*, Ankh-Hermes BV, Deventer

Moore, H.L.
1994 *A passion for difference*, Polity Press, UK

Murphy, R.
1995 Encounters: The body Silent in America, *Disability and Culture*, editor Whyte, University of California Press, USA, pp.140-158

Schain, W.S.
1980 Sexual functioning, Self-Esteem and Cancer Care, in *Body image, Self esteem, and Sexuality in Cancer patients*, S.Karger, New York

Secretariaat LCBB
1997 Borstreconstructie: Methoden en mogelijkheden, ervaringen en emoties, *Speciale Uitgave Mammazone*, 17e jaargang, september

Scheper-Hughes, N. and Lock, M.M.

Shilling, C.
1993 *The body and Social Theory*, Sage Publications Ltd, London
Sontag, S.

Vaith, J.M et al.
1980  *Body image, Self esteem, and Sexuality in Cancer patients*, (editor S.Karger), New York

Vonkeman, J.
1995  *Stuk, jonge vrouwen met borstkanker*, De kern, Baarn

White Stewart, M.W.

Yalom, M.
## Annex 1. GLOSSARY OF TERMS

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emic</strong></td>
<td>Perspective that uses concepts, categories and distinctions that are meaningful to participants in a culture (their point of view)</td>
</tr>
<tr>
<td><strong>Etic</strong></td>
<td>Perspective using concepts, categories and rules derived from science: an outsider’s perspective, which may not be meaningful to native participants in a culture (in broader view, comparing)</td>
</tr>
<tr>
<td><strong>Index</strong></td>
<td>Something (as a physical feature or a mode of expression) that leads to a particular fact or conclusion</td>
</tr>
<tr>
<td><strong>Introspection</strong></td>
<td>Reflection in which the anthropologist is his/her own instrument. Examination of one’s own thoughts and feelings</td>
</tr>
<tr>
<td><strong>Liminality</strong></td>
<td>The space “betwixt and between the normal, day to day cultural and social states” (Turner as in Little et al, 1998)</td>
</tr>
<tr>
<td></td>
<td>(In the context of illness) Periods of disruption of life in which structure and routine are abandoned and the state of being of those with chronic illness in which their being was judged as clouded and indeterminate. (Frankenburg and Murphy as in Little et al, 1998)</td>
</tr>
<tr>
<td><strong>Metaphor</strong></td>
<td>A figure of speech in which a word or phrase, literally denoting one kind of object or idea, is used in place of another to suggest a likeness or analogy between them</td>
</tr>
<tr>
<td><strong>Metomym</strong></td>
<td>A figure of speech consisting of the use of the name of one thing for that of another of which it is an attribute or with which it is associated</td>
</tr>
<tr>
<td><strong>Political process</strong></td>
<td>The way in which individuals and groups use power to achieve public goals</td>
</tr>
<tr>
<td><strong>Reciprocity</strong></td>
<td>A mutual give-and-take among people of equal status</td>
</tr>
<tr>
<td><strong>Social Network</strong></td>
<td>A set of direct and indirect links between an individual and other people</td>
</tr>
<tr>
<td><strong>Status</strong></td>
<td>A social position with a social structure: a role</td>
</tr>
<tr>
<td><strong>Symbol</strong></td>
<td>Something that stands or suggests something else by reason of relationship, association, convention or accidental resemblance; a visible sign of something invisible</td>
</tr>
</tbody>
</table>
Annex 2. TOPIC GUIDE

Dit onderzoek gaat over ervaringen van vrouwen met borstkanker die een borstamputatie hebben ondergaan. In dit onderzoek wil ik onderzoeken hoe vrouwen naar hun eigen lichaam kijken ervan uitgaande dat zij nu anders zijn dan de 'normale vrouw'. Ik wil dit onderzoeken omdat ik met name in de literatuur vaak tegenkom dat vrouwen na een borstamputatie zich minder vrouw zouden voelen, minder zelfvertrouwen hebben en hier veel problemen mee hebben. Ik vraag mij af of dit in werkelijkheid ook zo is.

Alle verzamelde informatie wordt vertrouwelijk behandeld, er worden geen namen gebruikt. Ik zal vragen of ik dit gesprek mag opnemen omdat dit het uitwerken van het interview vergemakkelijkt. Als dit een probleem is zal ik aantekeningen maken tijdens het gesprek.

Als je niet op een vraag wilt antwoorden, zeg het dan aub. Het gesprek kan op ieder willekeurig moment afgebroken worden.

Algemeen

Leeftijd
Scholing/beroep
Familiesamenstelling
Sociale netwerk
Gezondheidsstatus nu

Kun je in het kort vertellen hoe jouw hele ziekte proces is verlopen?
Zoals je al weet wil ik het met name hebben over jouw ideen over je eigen lichaam in dit hele proces.

Ervaringen met betrekking tot het anders zijn.
- Als je nu terugkijkt op je hele ziekte proces, wat heeft het meeste voor jou betekend, wat was het ingrijpend?
- Kun je iets vertellen over wat het voor jou heeft betekend en nog steeds betekend om een borst te moeten missen/een borst te hebben?
- Wat is er voor jou veranderd, heeft het je zelfbeeld veranderd? Zoja, op
- Hoe heeft je omgeving gereageerd op het feit dat je een borstamputatie hebt ondergaan, je partner, je kinderen?
- Hoe zijn de artsen en verpleegkundigen die je in het hele proces hebt gezien hiermee omgegaan? Is het na de eerste periode regelmatig besproken?
- Wat vond je het moeilijkst te accepteren?
- Heb je ooit overwogen een borstreconstructie te laten doen, zo ja, waarom? Zo nee, waarom niet?
- Wat vond je van je lichaam voordat je borstkanker kreeg, hoe belangrijk was je lichaam voor jou?
- Wat beïnvloedt jouw idee over je lichaam en is dit veranderd nadat je ziek bent geweest?
• Heb je jezelf geaccepteerd, ben je tevreden met jezelf, zo ja hoe komt dat dan, zo nee waarom niet
• Hoe denk je dat je zover gekomen bent
• Heb je hier iets aangedaan? Denk je hier iets aan te doen, waarom
• Hoe ga je om met mensen die zich afvragen hoe je dit kunt accepteren?
• Ben je betrokken bij een organisatie die vrouwen zoals jou assisteert? Indien ja, hoe helpt dit jou?
• Wil je verder nog iets vertellen of vragen?
• Zou je het op prijs stellen om een copie van de scriptie te ontvangen?

Ik wil je graag hartelijk bedanken voor dit gesprek. Ik vond het erg fijn dat je hier aan mee wilde doen. Ik hoop dat ik niet allerlei vragen heb gesteld die maken dat je je naar voelt. Mocht het zo zijn dat je na dit gesprek met allerlei vragen zit of nog meer wilt vertellen, wil ik je mijn telefoonnr. geven zodat je me kunt bellen. Ik zou willen vragen of ik je nog eens zou mogen bellen wanneer ik met de uitwerking van het interview tegen onduidelijkheden oploop.