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3.5 *"I never make love without my bra on". Bodily experiences of women with breast cancer*

Helle Ploug Hansen
Syddansk Universitet (Odense, Denmark)
[hphansen@health.sdu.dk]

Background

Improvements within the field of cancer treatment have meant that the number of women with breast cancer (1) who recover or survive for longer has increased. Some of these women, however, suffer from long-lasting side effects from their treatment, including fatigue, pain and lymphodema, as well as depression, sexual difficulties and emotional distress. Many women feel their breasts are an important part of their body image, and one way in which others can recognise them. A woman may love her breasts or dislike them, but she is rarely neutral (Young I. M. 1990: 189).

Cancer organisations, health care systems and private organisations in Denmark and abroad are involved in cancer rehabilitation programmes. The purpose of these programmes is to re-establish the physical, psychological and socio-cultural competencies (necessary skills and knowledge) of the affected individuals in order to enable them to work and live a normal life again. Cancer rehabilitation covers a wide range of different private and public initiatives, including psycho-social intervention, guidance and supervision, exercises, makeup workshops and a number of recuperative and convalescence schemes. Rehabilitation is a key word in the patient support work undertaken by the Danish Cancer Society. Alongside counselling centres, the Society also established a number of residential rehabilitation courses at different locations in Denmark between 1989 and 2001. Some of these courses focused on women's experiences of their altered bodies and body images (2).

Introduction to the Research

In the present article I draw on empirical findings generated primarily from an ethnographic fieldwork study with participant observation, and from ethnographic interviews at three residential cancer rehabilitation courses (each lasting five or six days) at different locations in Denmark. The first course, entitled "Get along again", was intended for women with breast cancer. It was held at a Folk High School in the eastern part of Jutland and it was attended by 18 women. The second course was entitled "Spa and Recreation". This course, for persons with cancer and their relatives, was held at a spa hotel north of Copenhagen. Four out of the seven women who attended this course had breast cancer. The last course was entitled "Body Image". It was designed for women with cancer and held at a holiday centre in the northern part of Jutland. Fifteen out of the 24 women attending this course had breast cancer. My data also stems from extensive interviews with 25 of the women conducted some two to three months after they attended their respective courses. A small number of the women had had a breast conservation operation, or a so-called a lumpectomy, while the majority had had a radical mastectomy. There were no significant differences between the two groups of women in relation to factors such as age, married status or education.

In terms of structure and content, the rehabilitation interventions offered in connection with the three courses stressed the distinction between the everyday social lives of the women within clearly structured systems of social relations such as family, house, neighbourhood, village, town or city on the one hand, and the rehabilitation interventions seen as 'not daily life structure' or 'anti-structure' on the other (TURNER V. 1974: 166-167). In terms of structure, the courses took place several miles away from busy cities near a forest, a park or the sea. The women had to leave their families behind and travel for a number of hours by train, bus, ship and/or by car to reach the residential course (many of the women had travelled between five and six hours) (3). Every day the women ate breakfast, lunch and dinner together, and on two of the courses the women shared twin bedrooms. Each course was organised and led by a health professional, be it a social worker, a psychologist or the leader of the patient organisation for women with breast cancer. The course organisers argued that nature (the ocean, trees, flowers, a lake) and special buildings (architecture and history) in themselves have a rehabilitative effect on women who have suffered serious illness, including treatments with long-lasting side effects. In terms of content, the women attended sessions of water gymnastics and floor gymnastics led by a health professional (a physiotherapist or a Mensendick method instructor). Every day and every evening, various seminars were conducted on topics such as the side effects of different treatments, bodily experiences, quality of life, makeup, style and colour, social issues, employment, etc. The content was primarily based on the experiences of the organisers who had all worked with women suffering from cancer for many years as counsellors for the Danish Cancer Society.

Community Spirit and Communitas

Each course began with a presentation round held a few hours after the women had arrived at their destination. The women sat down in a circle in the classroom that they would be using over the course of the next week. The course leaders had moved all the desks out of the way and put tissues within easy reach. They began by introducing themselves and giving some practical information about the course. Each woman then introduced herself, focusing in particular on the story of her illness and her expectations for the course. Many of the women ended their introduction by saying: "I don't think I need to say anything else because you know how I feel. We've all been through the same. We really do understand each other". The other women would look at the speaker, some would nod, others would be tearful, a few would pick up a tissue.

By choosing the same cancer rehabilitation course, by greeting their roommate and having their first meal together with all the other women, they had begun to create a community spirit: "we are all in the same boat" (some women actually used this expression). This community spirit was regenerated many times over every day on the different courses through small gestures including a hand on someone's shoulder, passing someone a tissue or giving someone a hug, and through superfluous utterances such as "we have something in common", "we understand each other". The anthropologist Jean Jackson states in her article that talking between patients with chronic pain often becomes superfluous because the communication had already taken place (JACKSON J. 1994: 218).

According to Turner, we can say that the structure and content of the courses foster the emergence of 'existential or spontaneous communitas': «[...] the direct, immediate, and total confrontation of human identities, which tends to make those experiencing it think of mankind as a homogeneous, unstructured, and free community» (TURNER V. 1974: 169). In the next part of this article, I will show how the existential communitas fostered in this way opened up a social space in which collective stories about bodily experiences and body projects could be produced and reproduced among the women.

Collective Stories about Bodily Experiences and Body Projects

Storytelling had a prominent place on all three courses. During the days and evenings the women produced and reproduced collective stories, often about their own bodily experiences of having had or still having breast cancer, and the different body projects in which they were engaged (such as makeup, clothes and wigs). I call them collective stories to indicate that they are constructed in the communication situations between the women. In the following, I present extracts from two collective stories that were produced between women who had had a mastectomy. I use the term story throughout this section rather than the term narrative, because a 'story' is an experience-near term connected to the women's experiences – everyone can tell stories – while a 'narrative' is an experience-far term associated with academic writings (WIKAN U. 2000: 217). To ensure that my empirical findings would be considered relevant for anthropological analysis, I employed the criterion that several of the women spoke about the same subject in similar ways within different contexts.

Conversation 1: Feminine dress for day and night

One evening, during the course entitled "Body Image", I took part in a 'style and colour' event. It was presented by a lady from a 'style and colour' company who had brought along a large number of different coloured scarves. She gave a presentation on dressing in colours that match our hair, eyes and skin colour and in a dress style that matches our body shape. During the presentation, she invited different women to join her on the stage. She put various colourful fancy scarves on the women to determine whether they were a 'summer', 'winter', 'spring' or 'autumn' girl, and she showed them illustrations of different dress styles for different body shapes. During one of the coffee breaks, I listened to three of the women who were having a conversation about colours and styles. They were standing around a small table and had good eye-contact with each other. Below, I quote the last part of their conversation which focused on the way in which a breast amputation had changed the way they dressed and the way they looked at other women:

> «I am more conscious today of wearing nice dresses, skirts instead of jeans for instance, a new blouse with bright colours and so on. I realised tonight that I'm a summer girl, really. I use more makeup than I did before, not only when I go to parties but also when I go shopping. I want to look as normal as possible» says Susan (4) (aged 53). Ann (aged 44) nods her head and continues: «I went to buy a new bra and knickers set just before taking part in this course. I paid more than 125 Euro for a set of 'Mary-Jo' (5) lingerie. When you've lost something you've got to have something else, I think».

Alice (aged 50), who has tears in her eyes, continues: «I understand you both, but I don't do that. I don't feel like putting on a feminine skirt or blouse... or a feminine night dress. I definitely don't want to look at bras, knickers or bikinis, because I think... or rather I know that one day I'll have two breasts again». Alice pauses briefly before continuing, with affection in her voice: «Normally I really do love feminine dresses, especially a nice feminine night dress. I have some in my drawer, but I haven't even touched or looked at them since my operation. Now I just wear a T-shirt to bed and a big sweater during the day» (she is on a waiting list for breast reconstruction by plastic surgery).

Ann responds: «I understand what you mean Alice. But I don't want to go through any more operations. I've had enough of hospitals». She pauses briefly. «But last spring I felt that I couldn't stand to look at other women's breasts any longer. Everywhere I looked, I saw women wearing tight T-shirts and low-cut dresses. You could see their cleavage. They were the lucky ones, while I couldn't get anything to work» she says, pointing to her breast. With a short laugh, she continues: «All those pert, pointy breasts. I didn't realise how much my breasts meant to me before I lost one of them».

Susan ends the short conversation by saying: «Yes, we have to learn to live our lives among women with two perfect breasts».

Conversation 2: Sex wearing a bra, or no sex at all

One evening during the "Get going again" course for women with breast cancer, a female politician and author was invited to talk about: "How to survive with cancer". Her speech touched on the subject of sexuality, and among other things she said: «I never make love without my bra on. It's not up for discussion. It's sex with my bra on or no sex at all». Later that evening, I joined a group of four women who were enjoying a glass of red wine. We sat around a table in a small kitchen. Two of the women had put their wigs on the table. They were making jokes about hot flushes and warm wigs. Suddenly Mary (aged 54) says: «What a woman. She wasn't afraid to share her thoughts and experiences about sexuality with us. I really admire her». She pauses briefly. The others nod, saying «Yes». Mary continues: «I wouldn't dream of keeping my bra on in bed, but I do wear a thin white night dress so my husband can't see anything. The rest is like it was before. I never take my night dress off when we make love, I just lift it up».

Kitty (aged 40) nods and says: «Oh. I do exactly the same. I keep my top on in bed, but not my bra. And I think I wear a top more often now during sex... maybe every time» she says, laughing. «I certainly didn't do that before».

Karen (aged 65) continues: «I have a boyfriend, and we have a sexual relationship. I wear pyjamas, but I never take the top off any more. I definitely wouldn't do that».

Doris (aged 43) reflects: «I kept a T-shirt on in bed at the beginning, you know – while I was having chemo and radiotherapy, but when summer came I took it off. I didn't like... it wasn't because I couldn't deal with my husband seeing me... but, but I felt that emotionally it was very difficult. I felt it was okay from my belly button down» she says, laughing a little, as the other women nod and look intensely at her. «We did have sex… that was important for me... I wanted to be normal... although there was a part of my body that I didn't like. And it was also because my husband wanted to touch other parts of my body» she says, referring to the time when she began to sleep without her T-shirt. «Now we try, but it's so... I cry every time he comes near my scars or the breast I've still got» she says in a trembling voice and with tears in her eyes.

Kitty puts an arm around her and they all sit quietly for a minute or so. Then Karen ends the short conversation on this topic by saying: «I never thought I'd be able to share experiences like these with anybody. It really is a great help to see that we understand each other, that we have similar problems, and most of all that we have to learn how to deal with them» (6).

The existential communitas fostered by, among other things, the various evening events paved the way for the women's conversations on topics of importance to them. In return, the women's use of collective stories and the process of storytelling maintained and strengthened communitas as this utterance from Karen shows: «It really is a great help to see that we understand each other, that we have similar problems… that we have to learn how to deal with them».

When I interviewed some of the women that had attended one of the three courses in their homes a few months later, they often referred to the generated "we understand each other" (communitas), concluding that joining a cancer rehabilitation course had taught them that women with breast cancer have a great deal in common. They repeatedly referred to two things, namely talking and swapping stories, etc. and being together. So communitas opened up a social space where collective stories about bodily experiences and body projects could be produced and reproduced among the women. When I interviewed Alice a few months after her course, she said: «I can't point out a specific moment during the course, or a particular event, and say 'that was the best thing', but being together and talking to all those wonderful women was absolutely fantastic. They showed me that life still has something to offer me. I gained new hope».

Ordering Experiences and Constructing Realities

Stories and the process of storytelling offered a way for the women of ordering experiences and of constructing reality (Bruner J. 1986: 11) and by doing so, the stories and the storytelling in themselves became rehabilitative. The women incorporated bits of the evenings' events, like the speech about not making love without a bra on, into their collective stories. And they used storytelling to organise and explore their new body experiences and their personal experiences, their body projects and their relationships with significant others, first and foremost their husbands or lovers (7). Communitas created a context which enabled the women to lend meaning to and make sense of the extreme difficulties they faced as a result of the total or partial amputation of one or both breasts. I will tentatively suggest that ordering experiences and constructing reality begin with the body: «That is, our understanding of ourselves and the world begins with our reliance on the orderly functioning of our bodies» (Becker G. 1997: 12). In the following section, I will focus on the content of the stories in an effort to understand the collective stories from a 'bodily theoretical perspective'.

The Body as Agent

The women's bodily experiences and body projects became the pivotal point of the collective stories. Take, for instance, the moment when Kitty says: "I keep my top on in bed, but not my bra. And I think I wear a top more often now during sex... maybe every time". I suggest that cultural inscriptions and historical representations quite literally constitute bodies, or body images, and help to produce them as such (Grosz E. 1994: X). In suggesting this, I am concurring with the latest research in the social sciences and humanities, where the body has been transformed from an object to an agent, and where biology is no longer seen as monolithic objectivity (see, for instance, Haraway D. 1991, Csordas T.J. 1994: 3, Grosz E. 1994). The body as agent becomes: «[...] an open materiality, a set of (possibly infinite) tendencies and potentialities which may be developed, yet whose development will necessarily hinder or induce other developments and trajectories» (Grosz E. 1994: 191).

As an open materiality, a woman's body becomes communicative; engaged in ongoing semiotic processes, a signifying and signified body interwoven with and constitutive of systems of meaning and representation (*ibidem*: 18). The women engage in different kinds of body projects such as breast reconstructions, feminine bras, breast prostheses, using more makeup and dressing more colourfully than before their sickness, as part of the rehabilitation process. Bodies act and react, body images are created and recreated, and the body may be said to create culture. The women's utterances within the collective stories can be seen as signs that refer to the way in which they look at their own, and at other women's, bodies. Susan, for instance, ends the first story by indicating that they must learn to live their lives among women with two perfect breasts. The word perfect is interesting, because it refers to a specific cultural understanding of women's breasts.

In Western societies, there is an extreme focus on women's breasts. As far as the woman herself, and others, are concerned her breasts are a daily visible and tangible reminder of her womanhood, a symbol of feminine sexuality and motherhood (YOUNG I. M. 1990: 189). The women's storytelling repeatedly attests to the emotional pain that results from being different, and to the struggle to reduce or eliminate that sense of difference from others (BECKER G. 1997: 16). Feminist authors, such as Iris Marion Young, argue that we experience our objectification as a function of the look of the other, and because breasts are seen as the visible sign of a woman's sexuality, the loss of a breast is socially interpreted as a corresponding loss of sexuality (YOUNG I. M. 1990: 189). The women view themselves as being at odds with what others – and they themselves – view as normal and perfect for their gender, age, and circumstances. Plastic surgery also facilitates the realisation of Western societies' phantasmatic breast ideal. The women's preoccupation with their lost breast as something that has to be dealt with, and their decisions to keep their chests hidden etc., make it clear that the sexuality they had recovered was recovered despite their mastectomy rather than through a joint exploration of the new (erotic) possibilities that mastectomy may offer (WEISS G. 1999: 62).

Some women who have undergone a mastectomy suffer a great deal because of these bodily 'inadequacies'. The attainment of 'perfect breasts' through plastic surgery may seem to play into the hands of sexual objectification. But these operations may just as often appear to the women who undergo them as a way of relieving sexual objectification, that is, as a way of drawing attention away from their breasts through their 'normalization' (*ibidem*: 61): «[...] breasts are an inherent bodily attribute subjectively lived and at the same time function as objects, both for men and for women» (GROSZ E. 1994: 108).

Bodily Space

From the women's ongoing storytelling, it becomes clear that there is a safety zone outside the body; a bodily space surrounding the subject's body which is crucial for the understanding of bodily experiences and body projects. This bodily safety zone is context-dependent, and it shifts and changes even for individual subjects:

> «[...] it is 'thinner' in some places (for example the extremities, which more readily tolerate body contact than other zones) and 'thicker' in others (which are particularly psychically, socially, and culturally 'privatized'» (GROSZ E. 1994: 79-80).

From the women's utterances it is obvious that their bodily space related not just to the body's surface but also to its surrounding space, which had been incorporated into their bodily experiences. The women considered any intrusion into this bodily space as serious a violation as the penetration of their bodies. The T-shirt, pyjama top or bra were used to denote and protect the border zone, and became the interface between the body surface and the body's surrounding space. This was particularly obvious when Doris described how she felt when her husband touched her body near her scars or the remaining healthy breast. Interestingly, the women in my study only referred to their remaining healthy breast as a potential source of illness, something that may also be affected by cancer.

Summary and Conclusion

In this article I have presented and analysed some of my empirical, ethnographic findings about the bodily experiences and body projects of women with breast cancer who have attended residential cancer rehabilitation courses in Denmark. I have demonstrated how the structure and content of these courses facilitated specific types of social bonds between the women, where communitas was produced and how it opened up a social space in which ongoing collective stories about bodily experiences and body projects could be produced among the women.

The loss of part of their body (one or both breasts, or part of one breast and perhaps a few or many lymph nodes under the arm) had created something like a 'point of no return'. Like Laurence J. Kirmayer, I would suggest that the collective stories I present show that the women's narrative coherence of the self has been shredded, making them more or less unable or unwilling to assimilate unpleasant but crucial facts about their bodies and their selves (Kirmayer L.J. 2000: 155). When Susan says: “I want to look as normal as possible,” or Alice says: “I know that one day I’ll have two breasts again,” they clearly indicate that they long for the time before their breast cancer developed. The social bonds created within the existential communitas helped the women to use collective stories and storytelling to gain new insight into their lives, and gave them new ideas for creating meaning, order and continuity following the unexpected disruption of their lives (the cancer diagnoses, the investigations, the treatments and the side effects).

On the one hand, the women’s bodies were involuntarily marked by the cancer, the investigations, the various types of medical and surgical treatments (incisions, scars, etc.) and the side effects (hair loss, pallor, etc.). On the other hand, their bodies were voluntarily marked by bras, colourful dresses, hairstyles, makeup, prostheses, exercises and habitual patterns of movement. These markings were actively sought out by the women in order to recreate and present their bodies as being appropriate for their cultural requirements (Grosz E. 1994: 142-143). They were not merely ‘technologies of power’ but actively undertaken as ‘technologies of the self ”, meaning that they required the active compliance of the women (Foucault M. 1988: 18).

Through storytelling, the women gave voice to their bodily experiences, their embodied despair and body projects, demonstrating that they strive to be normal; they described the types of body projects that preoccupied them, and their efforts to eliminate ‘the point of no return’. When the women confronted each other during the courses with stories of differences, of how they felt different from others, of how these differences could render social relationships uncomfortable and cumbersome, and of the emotional pain connected with these bodily experiences, they were given an opportunity to stop feeling alone and marginalised which helped them to live with their desire for normalcy and to acknowledge their differences (Becker G. 1997: 16).

Notes

(1) In 1999, 3,776 women in Denmark were diagnosed as having breast cancer.

(2) In 2001 the Danish Cancer Society opened the “Rehabilitation Centre Dallund” on Funen. 20 men and women take part in residential rehabilitation courses every week.

(3) Rehabilitation Centre Dallund is run along the same lines as the courses I have investigated, and the course content is very similar.

(4) Needless to say, all the names of the women in this article are fictional.

(5) 'Mary-Jo' is the name of a company that makes feminine lingerie for women.

(6) My interviews with the women who attended the three residential courses repeatedly return to these issues, especially when talking about 'womanliness' and 'sexuality'.

(7) The small number of women who failed to engage in the community spirit did not contribute to conversations like these, but from my vantage point as an observer they were few and far between.

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