Habituation to bodily changes after breast surgery in women

The larger project

Bodily Integrity in Blemished Bodies:

- Phenomenological examination of bodily wholeness in bodies that, biologically, are not “whole”

- Cases: facial disfigurement (+ usage of prostheses) after head – neck cancer; breast cancer; surgical breast reconstructions
Empirical-phenomenological study

Phenomenological theories on habituation

Empirical data

Breast surgery after breast cancer

- Incidence (new cases) breast cancer \(= 130 \text{ at 100,000 females every year (2007-2009)} \)* Netherlands
- Life-time risk \(= 12-13\%
- 5 year-survival: 80% if local and not spread: 90-100%

- Curative treatment: **Surgery** +....:
  - Mastectomy or "breast-saving"/lumpectomy + radiotherapy
  - Extra surgery: Axillary lymph node dissection
  - Extra treatment: radiotherapy, chemotherapy, hormone therapy, herceptin

*source: national cancer registration IKNL
From psychology to phenomenology

- **Medical psychology:**
  - “Body image satisfaction”
  - Coping

**Phenomenology of the body**

- How is the body experienced, lived (erlebt)? How does it appear?

- Non-intentional experiences (localized sensations, Leib experience) and intentional experience (body (part) as intentional object, Körper) (Husserl)

- Both experiences (intentional and non-intentional) have various degrees of explicit awareness/consciousness (Merleau-Ponty)

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**A body image scale for use with cancer patients**

P. Horwood, J. Fletcher, A. Lee, S. Al Ghazal

**BODY IMAGE SCALE**

In this questionnaire you will be asked about your appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and place a tick in the line alongside the reply which comes closest to the way you have been feeling about yourself, during the past week.

<table>
<thead>
<tr>
<th>Item</th>
<th>Not at all</th>
<th>A little</th>
<th>Quite a bit</th>
<th>Very much</th>
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<tbody>
<tr>
<td>Have you been feeling self-conscious about your appearance?</td>
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<tr>
<td>Have you felt less physically attractive as a result of your disease or treatment?</td>
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<tr>
<td>Have you been dissatisfied with your appearance when dressed?</td>
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<tr>
<td>Have you been feeling less feminine/masculine as a result of your disease or treatment?</td>
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<td>Did you find it difficult to look at yourself naked?</td>
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<tr>
<td>Have you been feeling less sexually attractive as a result of your disease or treatment?</td>
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<td>Did you avoid people because of the way you felt about your appearance?</td>
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<tr>
<td>Have you been feeling the treatment has left your body less whole?</td>
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<tr>
<td>Have you been dissatisfied with your body?</td>
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<tr>
<td>Have you been dissatisfied with the appearance of your scar?</td>
<td>Not Applicable</td>
<td></td>
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</table>
Bodily changes and adaptations from phenomenological perspective

1. The body becomes object of attention and awareness through disease, illness, pain etc. It manifests itself as “more” present, but in a “negative” way → dys-appearance (Leder)

2. Incorporation: mastering of skill and incorporation of artificial extensions and tools. Can habituation to bodily changes also be understood in terms of incorporation?

Central questions

- How does such a process of habituation look like after breast surgery? What does this process actually involve? What kind of embodied self-experiences are involved in this process?

- To answer these questions: let’s explore what women with disfiguring breast cancer say themselves → empirical study
Data collection plan

- Site: Academic hospital Maastricht
- Sample: 19 women: breast-saving (N=9), mastectomy (N=10); age 39-74
- Informed consent, fictional names for respondents
- 2 or 3 interviews per person, first interview 4 weeks after surgery, follow-up interval 4 months*
- Place: home, hospital or university
- Sometimes partner or relative present
- Digitally recorded, transcribed verbatim

* In addition: 2 women kept a diary (at my request)

In depth interviews

- Opening question: can you tell me in your own words what have happened to you?
- Topics:
  - Options and choices for treatment
  - Experience and perception of one’s body after treatment
  - Change and or continuity daily activities/habits
  - Role of partner, family, friends, fellow-sufferers and medical professionals
  - Normal routines and care for one’s body (dressing habits, cosmetics, sports and leisure habits, bathing and sauna habits)
  - Ideal of feminine embodiment
First analysis for this presentation

- Based upon 7 cases
- What kind of embodied self-experiences can be identified that involve either a facilitation or a frustration of the process of habituation?
- Limitation to 2 themes

Participants
(fictional names)

- **Kathy**, two-sided mastectomy (+ chemotherapy, hormone therapy), age 57
- **Donna**, one-sided lumpectomy (+ radiotherapy), age 50
- **Lisa**, two-sided lumpectomy, one-side radiotherapy (+ hormone therapy) age 62
- **Myryam**, one-sided lumpectomy + radiotherapy, age 61
- **Ann**, one-sided mastectomy (+ hormone therapy), age 68
- **Ellen**, one-sided mastectomy (+ hormone therapy), age 58
- **Ruth**, one-sided mastectomy (+ hormone therapy), age 72
The quotes in this presentation

- Fragments of oral interviews, transcribed verbatim, and translated from Dutch into English by me.

2 themes concerning habituation

- 1. Anticipating, preparing, imagining forthcoming changes
- 2. Presence/absence of body in daily doings
1. Anticipation, preparation

- Get rid of sick, malicious body part
- Parting from one’s breast/old body (fare-well ritual)

“Get rid of it”

“Yeah, well, there is a part missing, but I have to say it was sick...it is very unpleasant, but I am a rather commonsensical person; it had to be removed” (Ellen)

“I have had much pleasure of my body in my life. Therefore I am very well capable of giving up a part in order to stay alive” (Kathy)

“We have always said, well look, my wife has breasts. But if some part has to be removed, that’s just too bad. That was my opinion about it and perhaps it makes it easier for her” (Myriam’s husband)
“Parting from” 1.

- Rather explicit:

> “Two days before the surgery, I looked more often in the mirror. I then also touched and explored my breast with my hand, to experience how it felt and how it [always] has been. Touched and looked upon, together with my husband” (Ann 1)

“Parting from” 2

More implicit:

> “Yes, well, I said once to him: if you now look at me you can still see the two of them – to joke a bit about it” (Ruth and her husband)

> “When I took a bath, then I kind of thought – while pushing it [the breast] a bit – perhaps this will be gone soon. Yes, that is what I did until I knew for sure that I could have a breast-saving treatment. Then I tried to imagine how that would look like” (Judith 1)
Interpretation

In most cases of anticipation of bodily change; *external, distanced relation to one’s own body*

2. presence/ absence body

- Pain
- Explicit scar experience
- Disappearance (forgetting) of scar, loss and/or disease?
- Doubtful feelings
Pain → dys-appearance

This arm is. You know, it is. I have this uncomfortable sensation here, but well, presumably, that is part of it. It is a kind of neuralgia (Kathy 1)

But I feel that, for instance, now that I’m sitting here, and also when I lie down, I like to put my hands under my head, but that is not possible now. If I would do that; in less than a minute it would hurt me so much that I won’t be able to fall asleep (Ann 1)

Another meaning of pain

I must say that, so far, I have not really missed my breasts, since I have constantly pain there. It might sound strange but this pain has replaced my breasts (...) So far, I have not been able to really think that there is nothing left, since I constantly feel something there” (Kathy 2)
Explicit experience of scar

I told Jenny Slatman that I don’t mind to touch my breast. But to be honest, I find it rather unpleasant to touch the scar, since it is a bit swollen. (diary fragment Donna).

“In the beginning, it was really eerie. But now, eh, since the wound has been healed a bit, it obviously feels differently. And yes, you also get a bit used to it” (Ann 1)

“If I look in the mirror, I think ah, this has been done nicely (...) yes, it is tight, really very tight, very beautiful” (Ann 2)

“oh, yes for sure, it is a nice narrow line” (Kathy 2)

Dis-appearance of scar?

“Well, the scar reminds me of it, but I do not really dwell upon it” (Judith 2)

“Yes, well, I look at my scar every day, and now I’m used to it; it really is, well, it is not yet very pretty; it needs to heal” (Kathy 1)

“You forget about that numb feeling in the armpit and that strange feeling [in the breast]. Since you have the impression that it won’t really change anymore, it is like this is how it should be. Of course, I am very impatient, because it can take a long while before this will go away, if it will disappear at all. Most unpleasant is showering and drying myself off. If I touch my armpit with a washcloth or towel, I automatically produce funny noises and faces. Afterwards I always have to laugh about my own weird behavior” (Donna, diary)
Dis-appearance of loss/ disease?

I do no longer mention it, I mean specifically, that the breast is no longer there. Well you do mention it, but that is not in the sense that it concerns me” (Ann 2)

Actually, I pushed it away (...) pushed it away, moved it away, away with it, well I mean, I need the telephone [to remind me of my medication], but otherwise, it does not really occupy my mind (Lisa 3).

Doubtful feelings

Yes, phew, sometimes you do feel something, and then you wonder whether that would be normal, and yes, then you write that down, and then you touch it later again, and then it is gone, or something like that. I think that will remain, that, in fact you are constantly on guard” (Donna 3).

At one point you simply don’t know how it should feel. It was, then, and now as well, it was therefore very pleasant that the nurse examined [comparatively] left/right. Well, then you know, you have the feeling that everything is alright. (Donna 2)

Yes, I constantly feel and touch it. But you know here is this scar, and that feels like, so well, yes, I do feel and touch it more often than I did before. But for the rest, I try to go back to normal, everything like before (Judith 2)
Interpretation

- Pain: not only dys-appearance
- Evaluative experience scar: dys-appearance and eu-appearance (Zeiler)
- No complete disappearance or forgetting:
  - If an aim in itself, forgetting needs to be done
  - Bodily presence in bodily absence (embodied memorial?)

Preliminary findings:

1. **Empirical**: A small surgical intervention can have (unexpected) impact on process of habituation (doubts about how your own tissue must feel).
2. **Theoretical**: Explicit experiences of one’s body do not necessarily prevent process of habituation
Overall discussion

- Habituation to one’s altered body is not simply a process from explicit body experiences towards implicit body experience. Various explicit experiences (in which one may have a distanced relation to one’s body) may sustain the process:
  1. An explicit and external body experience can be helpful while preparing, anticipating bodily changes.
  2. Various explicit body experiences can be valued in positive way.
  3. Being reminded of a change is not opposed to regaining one’s bodily intentionality.

Literature

Thank you for your attention!

If you have questions or comments, please do not hesitate to contact me:

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