

Extended bodies

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Valorization

Extending discourses

With a life time risk of 1 out of 8, breast cancer is the most common type of cancer for women in Europe and Northern America. Being diagnosed with this disease not only confronts women with their own mortality, but also preludes an emotionally demanding and body altering trajectory of medical treatments and surgical interventions. Scarring, breast loss, lymphedema, balding, nausea, pain, fatigue, stiffness of the joints, increase in body weight, heart problems and loss of bodily functions are among the many physical consequences of breast cancer treatments. Understandably, living with and through this illness is a life changing process and severely affects the ways women experience and give meaning to their bodies. In this study, I describe and analyze how women's bodily experiencing in breast cancer, and sense making structures thereof, arise and take shape in relation to the different contexts in which these women live.

In my aim to unravel breast cancer experiences and sense making structures, I take an empirical-philosophical approach. Within philosophy, the question of how humans make sense of themselves is the domain of philosophical anthropology: a reflexive and theoretical discipline. In my study, however, I endorse the idea that philosophy, if it pretends to understand human existence, should not consist of reflection alone but should also include empirical research. This study therefore starts from the assumption that a person's experiences and sense making processes can be traced in their life story. By collecting and reading stories of (former) breast cancer patients, as well as the stories of others involved (partners, medical professionals), I tease out, articulate and interpret illness experiences.

This presentation of subjective breast cancer experiences is of great emancipatory value for women with breast cancer. While representations of living with breast cancer are no longer silenced and have acquired a steady place in public life, dominant existing discourses are restrictive in disclosing what it can and should mean to live through breast cancer (King 2004; Leopold 2000). Women who have (had) breast cancer are generally represented as unmarked, feminine and energetic survivors. As I show in this study, however, women's breast cancer experiences cover a wider range of self-definitions: they also present themselves as disfigured, disabled and ill. By attending to women's actually lived illness experiences, I escape the shackles of restrictive discursive frameworks and broaden public discourses about breast cancer. Such a broadening of discourses is of existential significance for those who live – and have lived or will live – with breast cancer. After all, a wider range of public discourses increases the possibilities to relate to relevant discourses in defining and making sense of oneself, one's life, and one's body. Even more, an extended range of public discourses about breast cancer may also be beneficial to people with ill, disfigured and disabled bodies in general. The way this study attends to a wide range of actually lived bodily experiences may function as an exponent of how one can and should disclose bodies.

In this valorization chapter, I will first elaborate on the prevalent existing discourses about breast cancer and discuss the importance of reflecting on and broadening these dominant imaginaries. Thereafter, I describe my concrete reflection and broadening

efforts. As we will see, these efforts revolve around breast cancer discourses in public life, in biomedical practices, and around larger discourses about deviant and ill bodies.

EXISTING DISCOURSES AND EXISTENTIAL ISSUES

Public discourses often disclose that living with breast cancer is an active journey in which women elicit their own journey of overcoming this illness and (re)turn to a normal embodied life, that is, to a healthy, feminine, and unblemished body (Carver et al. 1998; Sears et al. 2003). Such discourses enterprise individuals which actively shape their own illness experiences with the help of the monitoring, molding, and controlling activities of modern biomedicine (Ehrenreich 2001; Rose 2009). Granted, alternative constructions of an embodied life during and after breast cancer co-exist with these mainstream discourses. A magazine cover that displays a woman's permanently scarred, unbreasted chest, a TV show that features a woman's struggles with terminal cancer, and autobiographies which chronicle the severe pain that comes with having breast cancer are all part of these alternative breast cancer discourses. As the term suggest, however, in everyday life such alternative discourses are rather marginal and not (yet) very visible. Consequently, scarred, disfigured, incapable, or dying bodies, that is, bodies that cannot (fully) (re)turn to a normal – healthy, feminine, and unblemished – condition are virtually absent in the public realm. In my study I show, however, that these bodies are often the ones women actually live with in breast cancer.

With a prevalence of discourses that disavow actual breast cancer experiences, these women are presented with a possible existential problem. Ricoeur (1981) argues that without discourses that involve narratives that people can relate to in their stories about themselves, people may not only be unable to express themselves, but by implication, may also be inhibited in making sense of their lives and bodies. Then, mainstream discourses that adhere to women's opportunities to powerfully return to a normal life offer women limited guidance in giving meaning to their enduring illness experiences and their affected, disfigured and incapable bodies.

Over the last couple of years, more voices in disability and feminist studies call for making the multiplicity of actually lived illness experiences more public (Shildrick 2012; 2015; Scully 2013). These voices emphasize the existential importance of attending to narrations about bodies that fall out of the range of some generalized notion of what is normal or standard in public life. With my study about breast cancer, I not only tie in with this activist academic tradition, but I also contribute to diversifying representations about non-normal bodies in everyday life.

EXTENDING DISCOURSES AND EXISTENTIAL EMANCIPATION BEYOND ACADEMIA

By describing how women give meaning to their multiple illness experiences I mark out an extended range of possibilities of what it means to embody breast cancer. In women's stories, their normal as well as their non-normal aspects of their bodies become subject matter. They describe their (re-)breasted, unmarked, feminine, capable, and healthy bodies, but also their un/one-breasted, scarred, disfigured, incapable, leaking, painful, dying ones. Such descriptions in this study's chapters offer women who have (had) breast cancer a podium and a frame of reference within and through which they can express and give meaning to their illness experiences. However, the scope of emancipatory guidance of these chapters alone is fairly limited. After all, these chapters are (or will be) published as articles in academic journals, and thus mainly reach an academic audience. Therefore, sharing women's narrations and the study's results with a larger public is part of my emancipatory effort of allowing more women – and people with non-normal bodies at large – to make more sense of themselves, their lives and their bodies.

Extending discourses in public life – One of my efforts to share the findings of my study with a large audience is to publish illustrative breast cancer narrations online, namely on a bi-lingual (i.e. Dutch and English) project website, and by means of the project's Twitter account (see text-box a). Moreover, on this website and Twitter account, I publish the study's results and findings. Both the website and the Twitter account are a spin-off of the five-year research project *Bodily Integrity in Blemished Bodies* of which this study is part. Three researchers involved in the project, including myself, contribute to this website and to the Twitter account. With online media, we reach a broad, international public of academics, medical professionals, (informed) layman, breast cancer patients, and their close ones. In this sense, online media serves as a public platform of sharing and disseminating knowledge about what it means to live with breast cancer, knowledge which – as I argue in more depth in paragraph 6.5 – has a significant existential weight.

a. Online dissemination of findings

- ✓ Project website:
Mindthebody.eu:

Various examples of patients' experiences as narrated in the study, and summary of the published chapters 'The surprise of a breast reconstruction' and 'Blogging and Breast Cancer'.

- ✓ Twitter account
@mindthebodyeu:

Tweets: 209
Following: 191
Followers: 152
Likes: 34

Extending discourses in biomedical practices – My study’s approach and findings are particularly valuable and relevant in the context of medical practices around preventing and treating breast cancer. Women’s bodily experiences differ per individual and over contexts and time periods, and are often ambiguous, conflicting, very implicit or inchoate. Just as in everyday life, such experiences are not given much consideration in biomedical practices (see paragraph 5.5 and 6.5). With my study, I distribute new knowledge about breast cancer experiences to medical professionals. Moreover, by encouraging these professionals to attend to and tease out the complex ways in which women experience their bodies in cancer care, I aim to make professionals sensitive to the importance of including these experiences in the development, evaluation and adjustment of breast cancer care interventions, promotions and treatments. After all, medical professionals can only give adequate information and prioritize and select certain (medical) procedures when women’s experiences are drawn out. In teasing out women’s stories, I argue, medical professionals also actively enable and assist women in their existential emancipation.

First, I make the approach and results of my study known to medical professionals by collaborating with them in the context of data collection, analysis, and through writing articles together. I also disseminate the study’s findings by giving a presentation at the plastic surgery department of the hospital at which parts of the research was conducted, by discussing my findings with oncologists, social workers, and breast prosthesis designers at the same hospital, by co-supervising the master’s theses of two medical students, and by publishing my findings and results in multidisciplinary journals which (also) target an audience of medical professionals (see textbox b). Second, besides from disseminating knowledge about breast cancer experiences to medical professionals, I

b. Dissemination of findings to medical professionals

- ✓ Collaboration with medical professionals at the Plastic surgery department Medical Hospital Maastricht (MUMC+), from September 2011 onwards.
- ✓ ‘Women’s experiences of breast reconstruction’ – Presentation Plastic surgery department MUMC+, November 2012.
- ✓ Several meetings with oncologists, social workers, and breast prosthesis designers at MUMC+, November 2012 - April 2013.
- ✓ Co-supervision of master’s theses of two students in education program of Medicine at Maastricht University.
- ✓ Publications in academic, multidisciplinary journals which target medical professionals:
 - Leunissen, T., Boer, M.L. de, Hulst, R. van der, Slatman, J. (accepted: October 2015) ‘Exploring new dimensions in embodiment after implant based and autologous breast reconstruction’, *Journal of Plastic, Reconstructive & Aesthetic Surgery* 7, 31-40.
 - Boer, M.L. de, Hulst, R. van der, Slatman, J. (2015) ‘The surprise of a breast reconstruction: A longitudinal phenomenological study to women’s expectations about reconstructive surgery’, *Human Studies* 38 (3), 409-430.

also aim to assist and enable professionals in actively teasing out women's individual multiplicit breast cancer experiences. This, however, is not a straightforward task and requires specific narrative and interpretative skills. In my publications, therefore, suggestions are made to acquire such skills. For example, in my study on women's expectations about their breast reconstruction, tools are given for initiating a patient-doctor dialogue through which women may come to understand their (lack of) expectations and how to use this insight in the reconstructive process (see paragraph 5.5). Asking women open-ended questions like 'what is important in a breast reconstruction for you?', 'why?', 'what do you expect regarding your capability just after reconstruction?', 'and after a year?', 'can you imagine how your reconstructed breast will feel?' are a crucial part of this dialogue.

Extending discourses beyond breast cancer - The presented breast cancer narrations in this study are not only used for applying discourses about breast cancer in an alternative way: they also invite us to broaden discourses about disabled, disfigured, and ill bodies at large. As I argue in paragraphs 6.4 and 6.5, the larger structures about what it means to live with breast cancer are exemplary for a wider array of bodily deviance. By keeping these structures in mind, this study offers insights into lived non-normal embodiment, and as such, contributes to discussions about diversifying representations about such bodies. Moreover, by making public how people who live with bodies that are deviant to a societally shared notion of what is normal, more people are able to make more sense of their lived experiences.

c. Contributions to diversifying discourses about non-normal bodies

- ✓ Tweets on project's Twitter account: @mindthebody.eu
- ✓ Tweets on personal Twitter account: @Marjoleinlotte
- ✓ 'De grenzen van ons lichaam' [Title: The boundaries of our body] – Speaker Philosophy Festival Radboud Reflects, April 2016
- ✓ Interview with Maarten Meester about nippleless FEMEN-activists on Facebook. in: website Filosofie Magazine, May 2013, URL: <http://www.filosofie.nl/nl/content/35693/tepel-loze-activisten.html>

In several ways, I contribute to diversifying discourses about non-normal bodies (see textbox c). On the project's Twitter account and my personal Twitter account, I regularly post articles and statements about the stigmatization and marginalization of people living

with deviant bodies. Furthermore, as an invited speaker to a public philosophy festival I spoke about how people experience their bodies through interacting with materials and artifacts, such as prostheses and piercings. Herein, I extensively discussed one of my study's findings, namely the issue that how people experience their materialized bodies is heavily influenced by the cultural, normative context in which these interactions take place. After all, whether people experience their prosthetic or their pierced bodies as beautiful or capable is co-determined by cultural standards of what beauty and capabil-

ity is. On request of *Filosofie Magazine*, moreover, I gave an interview about the meaning of women's nipples in the public realm. In 2013, a debate was going on about Facebook removing photos of women who showed their breasts as part of their protests against patriarchal structures in society. As a way of getting through the 'scan' of Facebook, these women blurred their nipples before sharing their topless *selfies* online. In the interview, I posed the question why women's nipples are apparently not allowed to be seen on Facebook. This question is particularly important in the context of Facebook's sexist removal policy: photos of men's nipples are not removed by Facebook. I argued that women's nipples represent the intolerable, or 'abject' body: the body that leaks and wastes fluids with breast feeding, or that involuntarily changes shapes with temperature variations and with sexual arousal. Similar to one of my conclusions within my breast cancer study (see paragraphs 2.4, 3.5, 4.5, 5.5), I argue that we disavow this kind of body because it is a sign of disorder and of the limits of self-control, and thus a violation of the wish and hope for a clean and proper body. The abjectness of the nipples on the female body is therefore a body that is considered deviant from the norm, from what we desire. In the interview, I focused on how such an understanding of abject nipples may be stigmatizing and harmful for women.

The described efforts to contribute to bodily sense making processes show that this study aims to be beneficial for women with breast cancer, but also for people with deviant bodies in general. This study contributes to this kind of sense making by describing and making public a wide(r) range of possible embodied experiences. Such descriptions involve bodies that people can relate to in their own sense making, namely bodies that are healthy, two-breasted, unmarked, and capable, but also those that are ill, one/un-breasted, scarred, and disabled. The potential and hoped-for effect of these descriptions, moreover, is that they will inspire more extended storytelling about bodies in public life, and thus to have a large emancipatory value for all those people who live with non-normal bodies.

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