

Negotiating Gender in the Context of Hereditary Breast Cancer

Introduction and Problem Definition

Women's concept of gender, and their personal experience of female gender and the female body, can change when they encounter a health problem relating to female anatomy. The discovery of the hereditary BRCA-gene is such a health issue. The gene causes breast cancer in 80% of cases before the age of 50, and also significantly increases the chance of ovarian cancer after the age of 40. Women can be tested for this gene, and when they are found to possess it, choose between yearly check-ups or preventative mastectomy and potential reconstruction. They are also urged by their physicians to have their ovaries removed before the age of 40. Possession of the gene makes some women view their breasts as hostile, while others realize they view them as essential to their feeling of being 'a real woman'. A woman's feelings towards her body and her notions of gender influence the medical decisions that are made and vice-versa (Klawiter 2004, and Gifford, 1986).

A problem lies in the fact that the decision making process about these female bodies and the re-conceptualization of gender tied to it, take place within a medical institution that has the power to heavily influence both. Hospital policy dictates the appointments made, which staff is interacted with, the protocols of interaction, the environment and much more. Added to this is the unequal power distribution between doctor and patient, where the doctor has a privileged position as an expert and is able to dictate the terms of the interaction (Klawiter 2004, and Gifford, 1986).

Cultural scripts about femininity expressed by hospital staff through micro-interactions and discourse might make patients feel body-shame and cause them to conform to institutional norms about what is an appropriately gendered body (Klawiter, 2004 and Dolezal, 2015). If so, women's decision about how to modify their bodies is influenced by gendering of the hospital. Society and the medical institution leave their imprint on the female bodies of women with BRCA.

From a feminist standpoint gendering of female bodies by the powerful is highly problematic. From a humane standpoint engendering body-shame in patients going through trauma is to be avoided. And from the modern medical establishment's point of view, with its discourse and norms on the autonomy of the patients and their right to decide, influencing decisions about health by doctors on anything other than medical grounds is presumably unintentional. Change and awareness about the process could reduce body-shame in women with BRCA, give them more autonomy in their decision-making and greater agency over their bodies and gender-definitions. To

further knowledge on this point my research question is:

How are female bodies gendered through staff-patient interaction during discovery of the breast cancer gene, preventative mastectomy and reconstruction?

Theory

It has long been recognized that femininity and masculinity are social constructs and relations and that there are possibilities for change (Connel and Messerschmidt, 2005: 831). Connel and Messerschmidt conclude that gender is constructed actively and provides us with a model of multiple masculinities (2005: 830). I use a model of multiple femininities and propose that new specialized forms of femininity can be constructed by women with BRCA.

Connel and Messerschmidt also posited the idea of 'emphasized femininity' which is considered as an exaggerated form of femininity (2005: 833). On the basis of research of Klawiter (2004) I theorize that 'emphasized femininity' is the concept of femininity used by the medical profession when discussing breasts. I also hypothesize that due to insecurity about their ability to successfully perform their gender role, patients will gravitate towards enacting emphasized femininity. Connel and Messerschmidt (2005: 834) show in their overview of mechanism of hegemonic masculinity how "the enactment of hegemonic masculinity comes at considerable cost to the victors, in terms of emotional and physical damage" (Messner in Connel and Messerschmidt, 2005: 834). Hence the enactment of dominant femininity by patients with BRCA could also lead to emotional and physical suffering.

Disease regimes, or the structural shaping of illness experience by an institution, is a concept developed by Maren Klawiter in her paper "Breast Cancer in two regimes" (2004). She writes: "Experiences of disease are shaped not only by individual circumstances of disease sufferers, but by culturally, spatially and history specific regimes of practices" (Klawiter, 2004: 845). In her research she found that the disease regime of breast cancer is itself gendered. Klawiter states that her paper: "demonstrates how gender and sexuality are constituted within disease regimes" (2004: 845). In the case of breast cancer the experience of the disease and the experience of gender intersect, and the breast cancer regime influences both. Klawiter takes a macro-approach to study change in cancer institutions and there is a missing link to how these institutions influence gender in social processes. I create this link by focusing on how people make sense of breast cancer and female identity when

interacting with the medical institution.

The mainstream breast cancer awareness beginning in the 1990s frames the breast cancer survivor as an heroic survivor and “a woman whose femininity, sexuality and desirability were intact” (2004: 848). This breast cancer culture is characterized by the iconic pink ribbon. Although there have been challenges to this regime, the current medical establishment remains heavily influenced by this ideology (Klawiter, 2004). The staff's framing of the disease, specific vocabulary when dealing with a patient, and their symbolic acts of support will mostly be in line with the breast cancer regime of the hospital. Both the mainstream breast cancer awareness and the breast cancer regime in the hospital will decide what cultural scripts are available to the staff and patients when interacting in a clinical encounter.

In the interaction between staff and patient, both will make dramatic presentation based on a cultural script: “The cultural script guiding action includes ideologies, norms and rules, vocabularies, and implicit stocks of knowledge about which feelings should be experienced and expressed in episodes of face-to-face interaction” (Turner and Stets, 2006: 26). Actors have some dramatic license in playing the role, but if they deviate too far from the appropriate emotional script this will result in feeling shame and embarrassment. Who has power in an interaction depends on the quality of their performance, on the smallest amount of discontinuity between what they are feeling and the rules, and the use of micro-politics to manipulate the interaction. (Turner and Stets, 2006: 26).

In the clinical encounter the staff has the most dramaturgical power. The stage of the exam room or hospital ward is known to them and the performance given there is well rehearsed and often repeated. The medical staff can also be expected to have more experience in manipulating the specific interaction and using micro-politics. The feeling rules are also in favor of the physician as she is to play the expert, a role with considerable power. To the patient the stage is unknown and their performance is hampered by physical and psychological malaise. The patient ostensibly has more options for her presentation because less success is expected and demanded of the performance due to illness. However general feeling rules are in place for patients. Fear, sorrow, anxiety and helplessness are expected, as well as trust in the judgment and care of the medical personnel. The context, roles and rules of the clinical encounters make the patient relatively powerless, and likely to be guided by medical personnel as to what scripts and feeling rules to follow. If they do not follow the 'right' script, they feel shame and embarrassment (Horlick-Jones,

2010 and Dolezal, 2015).

There is a special kind of shame called body shame, first theorized by Aaron Lazare in 1987 and elaborated on by Luna Dolezal in her paper 'The Phenomenology of shame in the clinical encounter' (2015). Dolezal (2015) argues that patients often see ailments as personal shortcomings, and that interaction with medical personnel potentially involves humiliating exposure of these shortcomings. I theorize that illness related to female anatomy can be felt by women as failing to be a 'real woman'. Dolezal posits that “shame can be exacerbated or potentially created, or even incited by physicians through judgments and as a result of the power imbalance inherent to the physician-patient dynamic” (2015: 567). Where Dolezal limits her study to conceptualising body shame, I study how body shame has an impact on the sense of identity of patients.

In the case of breast cancer the physician-patient dynamic could incite or exacerbate shame about failing the ideal gender definition of being a woman. Hence the physician-patient dynamic can through shame about 'being/becoming less of a woman', have an effect on the decisions of the patient regarding choice of treatment and eventually the shape of the body. Women who have BRCA can be expected to feel their body is undesirable and to strive to regain the socially accepted body of a women. What this socially accepted body is, will be negotiated and redefined during the illness, especially in interactions where treatment and reconstruction of the body is discussed.

In the rhetoric around BRCA medical personnel draw upon two scripts when interacting with patients. Klawiter (2004) shows how femininity is one of these scripts. Another is the script of risk. Sandra Gifford in her work 'The meaning of Lumps' (1986) studies the use of risk language in consults of doctors with women at high risk of developing breast cancer. She writes:

When faced with management of a 'high risk' patient, surgeons have a tendency to treat risk as they would any other undesirable physical condition. Thus, we find that clinicians speak of risk not only as a sign of possible current or future disease, but also as something that resides in a particular part in the body and something from which the patient suffers (Dolezal, 2015: 216).

Like Dolezal (2015), Gifford found that doctors control the interactions with patients, and that the women in her research felt helpless and left to the mercy of the doctors. So it is no surprise her research showed that risk is experienced by lay women as the symptom of an illness. The breasts are experienced as symptoms of being ill, the disease lies in the breasts. Both patient and doctor

view the patient as sick, and as such, they view them as curable (1986). As the risk is perceived to lie in the breasts, the 'cure' for BRCA will be a mastectomy. Gifford (1986) elaborates on how risk of breast cancer effects women's conceptualization of health, but not on how it effects their sense of femininity and this will be my contribution.

Because the breasts are such a visual and central part of the gender ideal or the 'normal woman', the discourse of risk is in conflict with the discourse of gender. As is evident from the research so far presented, both discourses are present in the speech acts of doctors. For them there is an option for reconciling both scripts and using them simultaneously in consultation with patients: frame the natural breasts as risk factors and provide reconstruction options that are able to shape the post-mastectomy body into a body conform with the gender ideal.

From a feminist standpoint a better option would be to redefine femininity so that mastectomy is not perceived as becoming less feminine; or treating risk differently. A rhetoric backed by cultural mainstream logic used by the doctor as someone in a position of power can steer the interaction with, and feelings and decisions of the patient. In this situation resistance will be difficult and probably unsuccessful.

Bodily sensations play a big part in the experience of BRCA and are one of the main subjects of conversation with medical staff. Tom Horlick-Jones in his article 'Understanding fear of cancer recurrence in terms of damage to 'everyday health competence' from 2010, finds that fear of recurrence, and I argue also fear of occurrence when at high risk, leads to enhanced bodily awareness. I hypothesize that a patient diagnosed with BRCA is increasingly aware of the bodily sensations in her breasts. This might lead to increased anxiety about these body parts, as Horlick-Jones (2010) has found is the case for male patients who fear breast cancer recurrence. The increased awareness of the breasts and sensations in the breasts, many of which will be lost after a mastectomy and reconstruction, might also lead to a (re-)evaluation of the role of breasts in the sense of (bodily) self and bodily awareness of being a woman.

Unfortunately patients' sense of their body during diagnosis and treatment often clashes with the clinical rationalities used by hospital personal. Horlick-Jones (2010) concluded that patients who experience enhanced bodily awareness often come into conflict with medical staff and are labeled as behaving 'irrationally' and being 'bad patients'. He writes: "As detailed studies of clinical encounters have revealed, there exist a number of interactional mechanisms by which such conflicts may be repaired, usually in favor of the physician" (Horlick-Jones, 2010: 889). In the case

I will study this could mean the patients will refrain from challenging the physicians clinical rationale, and avoiding (discussing) personal reevaluation.

In my research I view the diagnosis and treatment of BRCA as a 'biographical disruption', a disruption of life which means that “significant personal and social adjustments are necessary to cope with the new situation in which one found oneself” (Horlick-Jones, 2010: 894). I link the concept of 'fateful moments' to biographical disruption. Fateful moments are moments that “are threatening to the individual's sense of existential security” (Horlick-Jones, 2010: 894). Where Horlick-Jones focuses on the damage to sense of everyday health competence, I focus on the damage to gender identity. I postulate that a person's sense of security concerning their womanhood is threatened by the diagnoses and treatment of BRCA, and that the 'significant personal and social adjustments' that are made concern reaffirming or redefining one's gender.

These adjustments are made in the routine, the everyday practice. Shutch and Luckman in Horlick Jones (2010: 894) write: “Attempts have been made to understand the impact of such events in terms of a loss of order, in a way which ultimately draws upon the phenomenological notion of natural attitude: the mundane recipe like expectations and routines of everyday life”. In the case of breast cancer this disruption and change in routines while in and out of hospital can range from clothing choices, use of implants, external prostheses, comportment, make-up and much more.

Operationalisation

I undertake this research from a woman's perspective, as well as a feminist perspective. Like Dorothy Smith advocates I will make my direct experience of the everyday world the primary ground of knowledge. I agree with Smith (1974: 11) “The only way of knowing a socially constructed world is from within”. My results will comprise both the social relations that led me to know, as well as the object of knowledge. My sociology is reflexive in that “one preserves in it the presence, concerns and experience of the sociologist as knower and discoverer” (Smith, 1974: 12).

Practically this means I begin from where I am bodily, develop systematic knowledge and later test this knowledge on my direct experience, as laid out by Smith (1974). She writes:

The actualities of our everyday world are already socially organized. Settings, equipment, environment, schedules, occasions as well as the enterprises and routines of actors are socially produced and concretely

and symbolically organized prior to our practice. By beginning from her original and immediate knowledge of the world sociology offers a way of making its socially organized properties first observable and then problematic (1974: 11).

It is exactly the aspects of daily practical routines within the hospital and their social production that I wish to observe. By experiencing, observing and interacting with the existing structure I can make knowable how routines in the hospital concerning BRCA patients are produced and how gendered bodies are socially and symbolically created through these routines.

I mean to make the organized properties of interaction between hospital and patient with BRCA observable by doing what Waquant (2015) calls 'enactive ethnography'. This means doing immersive fieldwork and 'performing the phenomenon'. I am able to do this because I have the BRCA gene myself and am currently a patient at the Daniel Den Hoed cancer institute of the Erasmus MC. By performing the phenomenon of BRCA I can develop in depth knowledge about the habitus of the patients and of the hospital as 'the cosmos under investigation'. This method is ideally suited to generate data that can provide an answer to my research question 'how are female bodies gendered by staff-patient interaction during discovery of the breast cancer gene, preventative mastectomy and reconstruction?'. It entails being present during the whole process and at all staff-patient interactions, as well as experiencing myself the effect of tests on the body, exposing the body, feelings of shame, involve me in talk about breast and femininity, and by observing and doing all small actions that can influence habitus but are not detectable by any other method, because they are not thought of (importance).

As Wacquant writes, I will be able to "detect and document the deployment of practical schemata that fashion practice; the cognitive, connotative and affective building blocks of habitus, whose layering and operations are fully open to empirical investigation" (2015: 5). As the answer to my research question will be the theory of a process, it is only right I should investigate by doing carnal sociology and "eschew the spectatoral viewpoint, grasp action-in-the-making, not action already accomplished" (2015: 5). Because my research subject is the gendering of bodies, the cutting open of bodies and the rearranging of tissue, viewing the person as someone of flesh and blood is imperative and it is most effective to study it from the position of someone of flesh and blood.

Although not mainstream, my approach is part of a growing genre of what Horlick-Jones describes as "publications by sociologists which are based upon their own first hand, involuntary experience of illness and healthcare" (2010: 886-887).

The first part of my research will be based on 'inadvertent ethnography' as I have already undergone referrals, diagnosis, consults with a social worker, surgeon and plastic surgeon, a mastectomy and (failed) reconstruction and hospitalization, as well as after care by a mamma-care nurse. My data here lies in correspondence, journaling, and memory of these events. This retro-active part of my research can be categorized as 'autobiographical sociology'.

The second part of my research is 'opportunistic sociology' as it takes advantage of the situation I am in to collect data for my research. Because of the failure of my reconstruction I will have several further consultations with a plastic surgeon, undergo two further operations, receive weekly injection for six weeks and receive after care from a mamma-care nurse. The data will consist of extensive field notes detailing actions, sequences, environments, talk with staff and other patients, emotions, bodily sensations and other observations. To these field notes I will add documentary materials such as bureaucratic paperwork, brochures from hospitals and patient organisations, photographs of posters and other information provided to me. I will focus on keeping my field notes dispassionate and with detailed description. In the end the data will resemble a descriptive diary. The end result must be systematic and principled research. Horlick-Jones argues that the method is valid because it is:

A method close to the diary-interview method developed over 30 years ago by Zimmerman and Wieder (1997). That method was used to gain access to social settings that were difficult to penetrate, by using participants as proxy participant observers. In my case, I have used my own experience to provide research access to the subjective world of the cancer patient. Without realizing it I was engaged in something akin to what Rodrigues and Ryave (2002) have described as 'systematic self observation'; an attempt to render visible certain aspects of the mundane subjective, and often sensitive, features of my everyday life as a patient (2010: 888).

In the case of patients with BRCA, their world is very inaccessible as it encompasses the inside of hospital consultation rooms and cancer/plastic surgery wards. My status as a patient there gives me access to all spaces, hospital staff, and other patients.

For the final part of my research I would like to increase the validity of my results by talking with, and if possible interviewing BRCA patients, as well as ask patients to keep diaries of their experiences to analyze later. From my position as a patient, talking with other BRCA patients will be possible because I am invited to a support group of fellow patients. This group might also provide a focus-group, interview participants and participant observers to keep diaries. Horlick-

Jones (2010) found that cancer patients were reluctant to talk about their experiences to most others, but open up to a fellow patient. I expect the same from women with BRCA and as such I am in a unique position to gather data in this field.

Conclusion and discussion

From a feminist perspective I want to chart if and how a dominant form of femininity is constructed in hospital by finding an answer to my research question 'How are female bodies gendered through staff-patient interaction during discovery of the breast cancer gene, preventative mastectomy and reconstruction?'. I want to give back to the community by distributing knowledge and suggestions on how protocol can be modified to allow for enactment of multiple femininities and the constructing of new femininity by women undergoing mastectomy.

To collect data I will conduct enacting ethnography and diary-interviewing to study the role of the body in the process of gendering. My research will add to the body of knowledge on local construction of gender and plurality of femininity as well as contribute to theory on the complexity of gender construction for women.

By taking a micro-sociological perspective on gender and the way definitions are negotiated, I cannot study how gender definitions are (re)produced by institutions, and how gender is embedded in the macro-structure. The embedding of gender norms in hospital policy, insurance, state policy and health-organizations is alas outside of my purvey. However because I study reproduction of a dominant gender role on the micro-level I will be able to analyze which aspects of the larger reproduction process are felt on the level of the individual. The discourse on female gender is produced by many institutions like the state, the hospital as a whole, the school, the family and more. My approach does not allow me an overview of gender discourse in society or the defense and challenges to these norms on the level of organisations. However elements of these discourses and of widely shared cultural norms around gender are present in the cultural scripts used by doctors and patients, and I will study how they are used and function in interaction.

By focusing on the experience of women with BRCA I might inadvertently enforce the split between female and male gender. Within this research I cannot study the whole gender spectrum. I dichotomize the experience of men and woman. Connel and Messerschmidt argue that researching gender should be done by “taking a consistently relational approach to gender” (2005: 837). My study could have taken a more relational approach by adding interviews or diaries from men with

BRCA or breast cancer and studying the effect of having a 'woman's disease' on their conception of masculinity. This relational aspect is beyond the scope of my research and the male experience of breast cancer and masculinity will remain unexplored. I will however advance knowledge on plurality of femininities, and show the process defining gender in action. This knowledge can be used to further study the plurality of gender identities in general and the gender spectrum.

Literature

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