

## **Our Genes, Our Selves:**

### **Hereditary breast cancer and biological citizenship in Norway**

Kari Nyheim Solbrække, Associate Professor in Health Sciences, Department for Health Sciences, Institute of Health and Society, University of Oslo, Norway, + 47 90016689, [k.n.solbrakke@medisin.uio.no](mailto:k.n.solbrakke@medisin.uio.no), corresponding author

Håvard Sjøiland, MD. Professor, Department of Breast and Endocrine Surgery, Stavanger University Hospital, Stavanger, Norway, Department of Clinical Science, University of Bergen, Bergen, Norway, [hsoiland@gmail.com](mailto:hsoiland@gmail.com)

Kirsten Lode, Researcher, RN. PhD Department of Research, Stavanger University Hospital, Stavanger, Norway, [kirsten.lode@sus.no](mailto:kirsten.lode@sus.no)

Birgitta Haga Gripsrud, PhD, Post-Doctoral Fellow, Department of Health Studies, University of Stavanger, Stavanger Norway, [birgitta.h.gripsrud@uis.no](mailto:birgitta.h.gripsrud@uis.no)

## **Abstract**

In this paper we explore the rise of ‘the breast cancer gene’ as a field of medical, cultural and personal knowledge. We address its significance in the Norwegian public health care system in relation to so-called biological citizenship in this particular national context. One of our main findings is that, despite its claims as a measure for health and disease prevention, gaining access to medical knowledge of BRCA 1/2 breast cancer gene mutations can also produce severe instability in the individuals and families affected. That is, although gene testing provides modern subjects with an opportunity to foresee their biological destiny and thereby become patients in waiting, it undoubtedly also comes with difficult existential dilemmas and choices, with implications that resonate beyond the individual and into different family and love relations. By elaborating on this finding we address the question of whether the empowerment slogan, which continues to be advocated through various health, BRCA and breast cancer discourses, reinforces a naïve or an idealized notion of the actively responsible patient: resourceful enough to seek out medical expertise and gain sufficient knowledge, on which to base informed decisions, thereby reducing the future risk of developing disease. In contrast to this ideal, our Norwegian informants tell a different story, in which there is no apparent heroic mastery of genetic fates, but rather a pragmatic attitude to dealing with a dire situation over which they have little control, despite having complied with medical advice through national guidelines and follow-up procedures for BRCA 1/2 carriers. In conclusion we claim that the sense of safety that gene testing and its associated medical solutions allegedly promise to provide proved illusory. Although BRCA-testing offers the potential for protection from adverse DNA-heritage, administered through possibilities for self-monitoring and self-management of the body, the feeling of ‘being in good health’ has hardly been reinforced by the emergence of gene technology.

Keywords: biological citizenship, hereditary breast cancer, subjectivity, gender, Norway

## Introduction

Scientific discoveries on human DNA have led to the rapid commercialisation of gene technology. In parallel, epidemiological and biomedical strategies have been developed to calculate the risk of disease and monitor population groups (Clarke et al. 2010).

Genetic testing is part of what Rose (2001) described as biopolitics, referring to how, through a growing interest in public health and so-called asymptomatic individuals, the state governs the population towards optimising its potential. Rose later elaborated on how the prevalence of gene technology in the 21st century has pushed the traditional notion of biology as destiny aside, replacing it with a new form of identity he termed *biological citizenship* (Rose 2007). Knowing one's genetic heritage and seeking treatment to avoid a disease or to maintain normality inverts the old story of disease, which has tended to centre on the authority of medical doctors. Instead, those of us who end up facing a positive gene test result are led to live, not on doctor's orders, but with 'Our Lives in our Hands' (Rose, 2007, p. 154). The term *patients in waiting* is another theoretical innovation produced by the shift to genetic techno science (Timmermans and Buchbinder 2010). It emerged from a comprehensive study of full sequence genetic testing of new-born babies in the United States and the subsequent human choices and dilemmas this has given rise to. When genetic testing can reveal information on a range of potential diseases that a new-born baby *could* develop, the baby becomes a patient in waiting, as well as a human in the making. In France the use of prenatal diagnosis (PND) and preimplantation genetic diagnosis (PGD) for hereditary forms of cancer have recently been made available (Dekeuwer and Bateman 2013). Patients in waiting who accept medical interventions to prevent the development of a potentially deadly disease form a new and an interesting group – they may avoid becoming sick by getting rid of an organ/organs. In the United States, women who undergo risk-reducing surgery after discovering they have a breast cancer gene mutation have been designated as *previvors*, as

opposed to *survivors*, of cancer. The most famous previvor is probably the American celebrity Angelina Jolie Pitt, who had her ovaries and breasts removed prophylactically (i.e. preventively).

In this paper we seek to elucidate the lived consequences of gene technology in Norway, since the discovery of the BRCA-mutations in the late 1990s. We ask *how* being a carrier of the gene mutation may come to shape subjectivities, and how women representing three different generations with inherited mutations who have developed breast cancer deal with their experiences. Are we, as Svenaeus (2013) has argued, witnessing the emergence of a form of *Homo pathologicus* supported by the emergence of genetic testing? Are Nordic countries producing a new and growing group of previvors, or patients in waiting, that may intersect with the type of American bio-identity so strongly embodied by Jolie Pitt?

To highlight these issues and how they may relate to Rose's claim about *gene technology as life itself* two empirical studies are considered. The first is a Norwegian newspaper representation of a young woman who has tested positive for a hereditary breast cancer mutation and subsequently had her breasts, uterus and ovaries removed prophylactically. Secondly, we analyse interview narratives from three Norwegian women spread over three generations, who all have inherited gene mutations and who developed invasive breast cancer.

### **Methods and analysis process**

The outline of this paper was sparked by a research seminar organised by one of the authors (KNS) to bring together Norwegian researchers for a critical approach to cancer survivorship. During one of the seminar discussions we found that although hereditary breast cancer attracts attention in the Norwegian public sphere, empirical research on the topic is scarce. A particular gap was identified in relation to gene technology as a biomedical intervention and

shaping force in Norwegian women's identity construction and embodiments. We subsequently decided to explore this research deficit further. Our approach to this has been analytical, firstly through a reading of a newspaper portrait of a young Norwegian woman who is a BRCA carrier, which has been informed by Kitzingers frame analyses (2007). Our aim was to examine a mediated case of Norwegian *previvorship*, which also turned out to present an unexpected example of how greater knowledge on genetic predispositions medically, becomes internalised and embodied, subjectively. Secondly, we were able to explore Norwegian *survivorship* through interview narratives from three women with a known BRCA mutation and an actual invasive breast cancer diagnosis. These three survivorship stories have been collected through the study 'I am not the same: women's experiences of breast cancer, loss of breast and reconstruction in psychosocial and cultural contexts' for which BHG was the principal investigator and HS and KL were engaged as joint researchers. The study received ethical approval from a Regional Committee for Medical and Health Research Ethics (REK Vest 2012/926). The three informants were: one young adult woman; one middle-aged woman; and one elderly woman. All three underwent double mastectomies, curatively on a cancerous breast, and prophylactically on a healthy breast. Although they all shared the same form of surgical treatment, their differences in age represented various time frames in the evolution of the new paradigm of predictive genetic testing in Norway within which, as we will show, their experiences were embedded in very different ways. Our exploration of these experiences and stories have been inspired by approaches to illness which attempt to address, describe and interpret embodiment and social embeddedness (Frank 2013; Kleinman 1988; Carel 2013) combined with what Locock et al. (Locock et al. 2016) recently has labelled 'breaches, cues and clues in the diagnostic assemblage' (p.85). An overarching objective, developed through our engagement with the data, has been to highlight these women's narratives not as expressions of one form of stable

bio-identity. Rather, we have come to see a more complex formation emerging: *assemblages of changing identities interweaving with the historical rise and consolidation of a new genetic era within one national context*. This complex encounter between individuals, families, technology, science, medicine, culture and society is what we attempt to detangle in this paper. One of our main findings is that, despite its claims as a measure for health and disease prevention, medical knowledge of the breast cancer gene may also produce severe instability in the individuals and families affected. That is, although gene testing provides modern subjects with an opportunity to foresee their biological destiny, it undoubtedly also comes with difficult existential dilemmas and choices that resonate beyond the individual and into different family and love relations. All in all we identified emerging outlines of bio-identities that to some extent appear to challenge the classic 2<sup>nd</sup> wave feminist insights and knowledge productions in relation to women's embodied sexual identity and experience, best exemplified by The Boston Women's Health Collective as *Our Bodies, Ourselves* (Boston Health Book Collective 1971). Hence, we have opted for re-naming this new medico-culturally mediated knowledge and identity transitioning as *Our Genes, Our Selves*, to give name to the new identify forms at stake in contemporary western women's lives. In order to do so in a critical and medically informed way, a more detailed contextualisation of BRCA1/2 is needed. Thus, in the following, we describe the rise of the 'breast cancer gene' as a field of medical and cultural knowledge, its significance in the Norwegian public health care context, and the escalation of a global illness phenomenon that this bio-scientific event seems to have generated.

### **The BRCA 1/2 mutation in a Norwegian context**

Knowledge of breast cancer genetics has developed over the last 20 years. In 1994, Mary-Claire King discovered a gene on chromosome 17 (BRCA1) that protects against breast and ovarian cancer (Dreifus 2015, February 9th ). It was subsequently hypothesised that mutations

in this gene would be associated with a higher risk of developing breast and ovarian cancer. The US corporation Myriad Genetics identified the BRCA1 mutation through detailed gene sequencing. The BRCA2 mutation was identified soon after in 1995.

Every year in Norway, around 3,000 women and 30 men are diagnosed with breast cancer (Cancer Registry of Norway 2014). An estimated 15-20 % of cases are due to familial inheritance (Lynch et al. 2008), meaning that most cases are non-hereditary. About 2% of breast cancer cases are due to a congenital risk through mutations in the highly penetrant BRCA1/2 genes (Normannsvik 2016) and may be as low as 1.7 % in Western Norway (Hoberg-Vetti et al. 2016). However, there is a higher incidence of BRCA1 gene mutations in southwest Norway (e.g. 3–4% in the county of Rogaland) than in the rest of the country (Møller et al. 2007). This led to more liberal criteria for genetic testing in Norway than in other countries in the early days after the scientific breakthroughs (Høberg-Vetti, 2015). The Norwegian Directorate of Health currently recommends that where ‘hereditary breast cancer is suspected a woman should be referred for examination by a clinical geneticist’ and followed up at specialist centers, in the hope of preventing cancer from occurring (Norwegian Breast Cancer Group [NBCG], 2016, p. 11). The BRCA1 mutation in particular, is high risk and associated with ‘aggressive’, highly malignant breast cancer that can develop at a relatively young age (normally over 50), and there is an increased likelihood of triple-negative breast cancer, which is associated with rapid disease progression (Høberg-Vetti 2015). However, it is hard to put a definitive number on projected lifetime risk, since many different mutations exist which may manifest themselves differently across families. Statistics on risk vary in the literature, but it has been estimated that the lifetime risk of developing breast cancer by age 70 with a BRCA1 gene mutation is 47–66% whereas that of developing ovarian cancer is 35–46% (Chen and Parmigiani 2007). The BRCA2 gene mutation carries a lower risk at 40-57% for breast cancer and 13–23% for ovarian cancer. In comparison, the ‘normal’

female population has a lifetime risk of developing breast cancer of about 10%. Men can also be BRCA-mutation carriers and are therefore recommended to get tested if they have a family history of breast or ovarian cancers. Men with a BRCA2 gene mutation have a greater risk of developing breast, pancreatic and prostate cancer than the normal population (Høberg-Vetti, 2015).

Ultimately, the aim of the preventive surgical approach advocated by health care authorities is to circumvent a rapid escalation of cancer that may be difficult to treat and has poorer prognoses than non-BRCA related breast cancers (Hagen et al. 2009; Møller et al. 2013). Historically, there has been a lack of consensus amongst medical professionals on BRCA patient guidance in Norway; there are also differences of opinion concerning best practice in different parts of the country (e.g. Oslo University Hospital have implemented full gene sequencing for all breast cancers). Consensus guidelines were not introduced until 2008 (Juvet and Norderhaug 2008; Norwegian Directorate of Health 2008). Due to the ethically challenging aspects of such genetic knowledge, the Norwegian Biotechnology Advisory Board and legislation through the Norwegian Biotechnology Act have imposed restrictions on access to sensitive information; only the patients may inform their treatment providers about their genetic composition.

Where a BRCA mutation is identified, annual magnetic resonance imaging (MRI) screening is recommended from the age of 25 (NBCG, 2016). Breast tissue may be removed as a risk-reducing measure (bilateral prophylactic mastectomy), generally recommended from the age of 35, and is thought to reduce the risk of developing breast cancer by 90–98% (Skytte et al. 2011; Heemskerk-Gerritsen et al. 2013; Norwegian Directorate of Health 2008; National Breast Cancer Group 2016). A prophylactic mastectomy entails removing all tissue in both breasts, including milk ducts and sensitive nerve tissues. The nipples may be preserved, but lose their erogenous sensitivity.

Even before the discovery of BRCA1/2, prophylactic breast removal occurred with women who either had a previous breast cancer diagnosis and/or a heavy family history of breast cancer (DeShazer 2013). Today, given the knowledge about BRCA1/2, all women with a gene mutation should be advised to consider a bilateral prophylactic mastectomy, which may be accompanied with immediate reconstruction (silicone or saline prostheses). This is a time-consuming and resource-intensive operation, and most patients have a relatively long recovery period - in Norway, these patients usually require two months sick leave.

### **The rise of ‘the breast cancer gene’ and a new ‘disease regime’**

Klawiter (2004) showed how breast cancer as illness experience is constituted beyond individual circumstances and pathologies; it is also shaped structurally from historically specific processes of change, such as new forms of social activism like feminism, women’s health movements, consumer organisations and cancer activism. She introduced the term *disease regimes* to describe the intricate interplay between social structures, cultural factors and subjective life experience related to breast cancer. While breast cancer has been the subject of considerable activism since the 1970s (Gripsrud 2008; Yalom 1998), *genetic predisposition for breast cancer* is a relatively new health phenomenon that has not yet manifested itself as a unified movement, with the exception of the US advocacy group Facing Our Risk of Cancer Empowered (FORCE). Jolie Pitt quickly became a prominent international spokesperson for US previvors, and in line with FORCE’s message, has promoted genetic testing and risk-reducing surgery as a form of personal empowerment. We therefore seek to highlight aspects of a relatively new disease regime based on hereditary breast cancer, previval and survival, and attempt to show how these interlinked phenomena are expressed, lived and articulated in a Norwegian context.

Shortly after the scientific discoveries of BRCA 1/2, the mythical story of *the breast cancer gene* started to emerge. Centring on media representations of BRCA and its social significance, Henderson and Kitzinger's (1999) content analysis of British media coverage stands out as an early documentation of the sociocultural effects of the gene discoveries. Researchers found that hereditary aspects of genetics and risk received widespread coverage through various media outputs. Much of the attention was dedicated to individuals from high-risk families facing difficult choices associated with prophylactic mastectomy. Such stories were deemed valuable by editors in terms of their explicit *human interest* angle. In their study, Henderson and Kitzinger (1999) showed how BRCA emerged in the media as a new and attractive theme providing strong dramaturgy related to topics of life/death, youth/fate, healthy/sick, mother–daughter–grandchild, and breasts/amputation. Through focus group interviews, they found that these emotive human interest stories captured the public's attention and provided them with a particular understanding of this new illness phenomenon. Since then countless media contributions have been made on BRCA, including the digital formation of dedicated websites and user forums. Mainly in an Anglo-American context, BRCA carriers have opted to tell their personal stories through literary autobiographical work in the tradition of breast cancer survivors (Deshazer, 2013). In Norway, similar types of illness-specific representations on BRCA are rare, although we know of various blogs and closed Facebook groups. We are interested in exploring whether the dramaturgy and language of the Anglo-American mediations and storylines on BRCA have entered the Nordic context, and what, if any, form of subjectivity is evident in Norwegian previvors' and survivors' narrative accounts. Nevertheless, we must also acknowledge that new forms of bio-identities in Norway cannot be viewed as isolated cases tied to their geographic locations; rather, they are psychosocial (Woodward 2015), emergences in otherwise globalised and media-centric

lifeworlds where the local, national and international intersects in complex ways (Ehn et al. 1993; Gullestad 2002).

When Angelina Jolie Pitt announced that she was a carrier of the BRCA1 gene mutation in 2013, she sought to empower other women. In two letters to the editor of the *New York Times*, she expressed her thoughts on having a ‘faulty’ gene (Jolie Pitt 2013. May 14th; Jolie Pitt 2015, March 24th). The first one, opened like this:

MY MOTHER fought cancer for almost a decade and died at 56. She held out long enough to meet the first of her grandchildren and to hold them in her arms. But my other children will never have the chance to know her and experience how loving and gracious she was.

We often speak of ‘Mommy’s mommy’, and I find myself trying to explain the illness that took her away from us. They have asked if the same could happen to me. I have always told them not to worry, but the truth is I carry a ‘faulty’ gene, BRCA1, which sharply increases my risk of developing breast cancer and ovarian cancer. (Jolie Pitt, 2013)

The letter starts off evocatively with a personal tragedy through a reference to the dead mother figure. Jolie-Pitt provides a vivid image of the double grief she experienced as she lost her mother, grandmother and aunt to cancer and started facing the possibility that she herself could inflict such a loss on her own children if she did not take control of her genetic destiny. Reading the letter, we get the feeling that the women in this family are relentlessly persecuted. However, Jolie Pitt refuses to become a victim: She presents herself as confronting a pointlessly destructive genetic material. Thus, she arises through the letters, like a real-life heroine – an empowered *doer* and not a predetermined victim, a *done-to*. As a media personality, Jolie Pitt represents a formidable force. She is a highly profiled, glamorous and well-paid representative of Hollywood’s culture industry. But in the letters, her success and standing as a megastar are completely overshadowed by the tragic and empathy-evoking drama surrounding her personal genetic family tree. These two aspects are reinforced by the choice of genre and wording, which subtly evoke the supreme cultural gestalt of the breast cancer survivor’s narrative, often characterized by an evocative staging of tragedy, adversity

and defiant heroism through personal testimonials (Gripsrud et al. 2015). Jolie Pitt's previval stories attracted unprecedented media attention, propelling the topic of BRCA into the global media spotlight. Two open letters from one very special woman quickly became a worldwide enlightenment campaign with material consequences for patients in waiting (Evans et al. 2015). So much so, that we can now speak of the 'Angelina Jolie effect', which in the UK, has been linked to an unexpected twofold increase in the number of referrals for genetic testing and risk-reducing surgery (Theissen 2015). The Angelina Jolie-effect has also been observed in Norway (Jakobsen 2014; Thue 2015). We speculate whether the astonishing increase in bilateral mastectomy with immediate reconstruction amongst US women with unilateral breast cancer who do not have a genetic risk-factor (Lagnado 2015 ) might also be related to the Angelina Jolie-effect and a rather misconstrued self-assessment that 'taking it all' is a stronger guarantee against recurrence (medical experts say this is really not the case). Such knowledge-effects demonstrate that biomedicalisation is a complicated process in which scientific and technological advances in genetics are gradually implemented in clinical practice, whilst at the same time, a single pop-cultural phenomenon can trigger a sudden increase in treatment demand, including over-treatment of otherwise healthy organs.

Through her openness about her gene heritage and her strategies for tackling it, Jolie Pitt undoubtedly sought to advocate the 'common good'. However, there is reason to question how exemplary her personal story is as a public health information project. According to her letters, she was told by medical experts that she carried the BRCA1 mutation, which entailed an 'estimated [...] 87 percent risk of breast cancer' (Jolie Pitt, 2015). With such a dramatic statistical risk scenario, we would argue that BRCA1 is portrayed as a *de facto* predicted breast cancer diagnosis, making Jolie Pitt's empowered choice of risk-reducing surgery appear as an indisputably life-saving act, in response to a destiny that is statistically guaranteed to take its course. However, the figures currently presented at a respected US

public health website provide a somewhat different risk scenario, illustrating how such calculations have fluctuated through the years since the genetic discoveries: BRCA1 is now estimated to represent a 55–65% lifetime risks of developing breast cancer; for BRCA2 the risk is about 45% (US National Cancer Institute, 2015). Since there are no longitudinal population studies comparing cancer risk among samples with and without gene mutations, the statistics are likely to be adjusted again in future. Until science is able to produce more personalised knowledge on risk calculations, patients in waiting will have to base their decisions in relation to testing and prophylactic treatments on somewhat variable figures.

### **BRCA previvorship in a Norwegian context**

Norway has seen several prominent figures that have fronted their breast cancer survivorship publicly, but so far there have been no celebrity profiles that have spearheaded the BRCA issue, specifically. Despite this, there are cases showing that when it comes to hereditary breast cancer and preventive mastectomy, the Anglo-American emotional dramaturgy, typified by Jolie-Pitt's media coverage, seems to have been adopted by the Norwegian media through a focus on personal testimonies from 'ordinary women'. A typical newspaper headline emphasises the shift from doctors as lifesavers to patients as lifesavers for themselves, emphasizing the human interest angle. The interview analysed below was printed in the Norway's largest newspaper, *Aftenposten*, under the headline '*Reduced her risk of cancer by 80%*' (Dommerud and Westerveld 2014). The subject was a young Norwegian woman who had opted for a preventive bilateral mastectomy without reconstruction, on the basis of the following logic:

*'My breasts are not who I am. I did not want any more surgical procedures or side effects. I want to be able to monitor my own body, and with my breasts completely gone it's easier to see if a new lump appears.'*

Thanks to the gene test and the choice to remove her breasts, ovaries and uterus, the risk of developing these types of cancer was reduced by between 70 and 80%. It was important to Louise Skak that she had the option; her sister never did.

*'I chose to take the test. I then had the opportunity to make an active choice about how to proceed. I have had healthy organs removed, but I have taken preventive measures and am not therefore likely to develop cancer. I'm not even half way through my life, and aim to live to be a 100. I can do this because I had the opportunity to take a gene test', she said. (Dommerud & Westerveld, 2014, our translation)*

Compared with the media sensation and emotional rhetoric that followed the BRCA diagnosis of Jolie Pitt, the framing in the Norwegian case seems rather sober. The interviewee is not particularly glamorous, conventionally feminine or famous; instead, she appears to be just like any other young Norwegian woman. Nevertheless, the phrasing used ('thanks to the gene test') clearly shows how the carrier of the gene and the media representation of her choice intertwine and reinforce the message that 'testing saves and prolongs lives'. In this way, the interview represents a Norwegian patient in waiting or previvor who resonates well with a larger discursive shift in global health in which individuals are increasingly positioned to take the full responsibility for his or her own future health.

Yet there are several contrasts between our US and Norwegian examples that should be highlighted. Jolie Pitt opted for immediate reconstruction of her breasts, appearing on the red carpet post-surgery, as 'unchanged' – a miraculously identical version of her former figure, and subsequently framed in the media as she herself had expressed: 'no less a woman' (Jolie Pitt, 2013). The Norwegian woman, in contrast, is presented in the interview as a person without breasts, ovaries or uterus – radically distinguishable from conventional femininity. This body bears visible signs that something has been sacrificed to preserve or protect life; yet, the woman is willing to flag her difference and comes across as being well-adjusted to her loss of several sexual organs. For instance, she does not have a problem baring her mastectomy scars in the communal showers at the swimming pool. To our knowledge, the decision not to have reconstructive surgery is still fairly unusual both in Norway and the

United States – most previvors opt for reconstruction. However, there are also exceptions to this norm in the United States: Individuals and patient advocacy groups like Flat & Fabulous have publicised their decisions not to have reconstruction surgery or their removal of implants due to plastic surgical complications after either preventive or curative mastectomy, appealing to readers with same empowerment slogan as Jolie-Pitt. Previously, this ‘flat’ practice was linked to alternative identities and marginalised positions, particularly amongst women whose identity is not tied up with a heteromale gaze.

In our Norwegian case the interviewee is presented as an ordinary young woman whose decisions about surgical treatment were *not* based on any form of protest against social norms. However, the rationale she offers is a testament to her awareness of a normative cultural link between femininity and the breast with which she does not identify. The particular framing of her gendered body may be interpreted in light of the hegemonic position that sports and athleticism has had in the Nordic region (Slagstad 1998) to which many Nordic women subscribe (Lindelöf 2015). It may also be that the traditional egalitarian social structure in Norway is still characterised by an investment in a robust body for working and parenthood as opposed to an aesthetic body and non-reproductive sexuality. If so, these sociocultural ideals may intersect with a distinctively Norwegian pragmatism associated with an agrarian history where elementary bodily functions, including lactating breasts, have been less subject to taboo, than in more classed, aesthetically sophisticated and urbanized modern cultures (Gripsrud, 2008). In such a pragmatic and traditional meaning system, a breast prosthesis contour (without sexual or lactation functions) may be deemed less significant than one might expect from a contemporary late capitalist culture, where physicality is increasingly invested in optimizing appearance and sexual desirability.

An even more interesting aspect in the interview is that the woman’s choice not to reconstruct her breasts is accounted for by her wish to be more able to detect lumps. As we

see it this may represent something much more profound than liberation from normative femininity; it expresses an anxiety related to ‘no longer trusting the healthy body’, or what Svenaeus (2013) has characterised as *Homo pathologicus*. The term describes how divergence and abnormality, which have traditionally been managed by the biomedical domain through intensified access to and dissemination of medical knowledge, have glided into the late modern human lifeworld governing perception of our bodies and our selves.

### ***BRCA and breast cancer survival in a Norwegian context***

We will now turn to the stories of three Norwegian women with a known BRCA mutation and an actual invasive breast cancer diagnosis. The data were collected as part of ‘I am not the same’, a larger qualitative study on Norwegian and American women’s experiences of breast cancer. These three narratives serve to improve our understanding of the web of subjectivities that gene technology both enables and produces. Participants were recruited from a regional health trust in Norway, and interviews conducted a few weeks after surgery. Our analysis explores how the historical emergence of genetic testing in Norway becomes interwoven with the individual woman’s lifeworld. We consider the extent to which different types of knowledge coloured these women’s thoughts, feelings and actions before and after the cancer diagnosis.

These stories proved particularly thought-provoking as we discovered that the informants represent three generations of Norwegian women who had lived their adult lives before, during and after the discovery of BRCA mutations. All three women have been de-identified and provided with pseudonyms. The woman we refer to as Anna is the oldest; she has several children and grandchildren. She had both breasts removed, and chose not to have reconstructive surgery. Bente is middle aged and has a teenage daughter. Bente also had both breasts removed. She initially wanted reconstruction surgery immediately following breast

removal, but this option was not available on the day of the operation. Rather than wait a week for reconstructive surgery, she felt she had to rid herself of the cancer as quickly as possible, and has therefore remained flat. Cecilie is the youngest and has a stable relationship with her partner, without children. She has had both breasts removed and received immediate reconstructive surgery with prostheses.

*Anna - Generation I (70+ years)*

Anna is retired and has had breast cancer twice. In the late 1990s, she found a lump in her breast. At that time, the surgeon recommended breast-conserving surgery followed by radiotherapy. Seventeen years later, cancer was again detected during an MRI routine scan of the same breast, and she was subsequently diagnosed with a local relapse. This time around, she wanted both breasts removed, which was also the surgeon's recommendation. Shortly after the first diagnosis, Anna was genetically tested, and learned that she was a carrier of a hereditary BRCA gene. She was at that time, advised to have her ovaries removed but medical professionals did not advise her to remove the breasts .

It was not exactly a bombshell [at that time], because I had already lost my sister to cancer a year earlier. I knew then...we were after all called to an appointment at the Norwegian Radium Hospital and tested. And then I learned that I had the gene that she had, and my father had the gene. So it's just...at that point it was only us who had the gene, but now my sister's daughter has been tested, and unfortunately she also has the gene.

Basically, I would say that I've been very lucky. First and foremost, I have always been strong in myself, both when others and I myself have faced illness – I have always managed to cope with it well. I have never let it get me down, either then or now...instead I thought 'I will keep going, I can do this'. And I managed for so many years before it [the cancer] reappeared. And then my grandchild [...] she said, 'Granny, you can do it this time as well. You managed it last time too'. They had never seen that I have been...felt sad about it, so I was absolutely determined when it returned: I want to get rid of both breasts, even though the cancer is just in one, I don't want to go through this again. But I was lucky because I was able to say it while I was there, and then the lady [health care staff who was there] with the doctor was so happy that *she* didn't have to say it, because she was going to recommend me having both removed. But I had already decided that they would both be going. She said that I could risk it reappearing if I didn't do it now...But I've been told that it might show up in other parts of my body, it hasn't made me immune to cancer. So, I'm very much aware that it...But I was healthy when I came in [to the clinic] and healthy when I left. I haven't had any problems, nothing.

When the cancer returned the second time around, Anna noted how the health care personnel seemed relieved about not having to tell her that both breasts should be removed. She had already experienced the challenges related to a breast cancer diagnosis and adjuvant treatments, like chemo and radiation. These life experiences drove her decision: By removing both breasts, BRCA-related cancer risk could be drastically reduced, although Anna is also clearly aware that breast cancer is systemic disease ('it hasn't made me immune to cancer') and that a mastectomy is not a guarantee against relapse. To us, this statement of sober realism ("I'm very much aware that it...") about cancer recurrence is abruptly juxtaposed with her conception of good health ("I was healthy when I came in...healthy when I left"), suggesting that Anna does not see herself as sick despite having had breast cancer twice. In this sense, she is not a typical representative of a bio-identity; rather she represents a kind of traditional stoicism where, in the absence of bodily suffering, one considers oneself to be healthy. When Anna uses the word 'sick', she is describing an experience rather than a clinical status – *to feel sick is to feel poorly*. Perhaps this distinctive personality feature has protected her from some worries. Knowledge of her genetic inheritance is something she has been able to live with without pathologising herself: Anna comes across as a vivacious character: a confident mother and grandmother and a good and trusted friend to many. She sees herself as a role model for others in the same situation. She has met many people with cancer and is keen to show others that it is possible to have a good life after cancer:

I usually tell everyone: I have no reason to complain. Because I've been so lucky with everything. I have, unfortunately, lost many that... [...] I feel it's so important to get across how well things can go. It goes so much better I think when you have people around you, you can be together. I think those who have the worst time are those who don't want to talk about it, I think they must be suffering terribly. Our family has been open about everything with others, including the children and grandchildren and the rest of our gang, we talk openly about everything. And I think it's fantastic that we don't keep anything hidden. My two young grandchildren are now the most important ones in it all. Occasionally when they come, I have not [Unclear. Have not managed to?] put my blouse on. And then they sometimes say: today we have bigger [breasts] than you, Granny. [Laughter] And I think it's good that we can have a laugh and be accepting of it, they see that it is going well. But I have indeed been lucky, as I like to say... All the positives that I have experienced despite everything.

A key facet of Anna and her story is her openness. This social sharing is a distinctive characteristic of the Nordic cultures and a resource that Norwegians see as a crucial element in tackling serious illness (Gele and Harslof 2010). Recent studies of cancer survival in Norway have also revealed the crucial role of close social relations for patients' who face considerable emotional, existential and physical challenges (Gripsrud et al. 2014; Kristvik 2012; Sekse et al. 2012; Solbrække and Lorem 2016). Anna expresses her feeling of being unconditionally loved and accepted by her husband, children and grandchildren. In her family they can, for example, joke about her lack of breasts inter-generationally. Principally, it is vigour and joy in life which characterise Anna's account of having survived breast cancer twice due to a BRCA mutation. Nevertheless, there is no doubt about the burden that learning about the gene has placed on her life and the next generations; it is something that explains great human loss in the family, and causes concern for the coming generations. The gene has a specific meaning as an explanatory model for historically inexplicable deaths from cancer, whilst framing life as a lottery – Who is carrying the dangerous mutation and who is safe? Anna tells her illness story with great stoicism, but it is not completely devoid of vulnerability. The BRCA-theme emerges not only as a neutral medical fact but also as a more psycho-symbolic depiction of a terrifying force that robs her of family members: 'This gene we have is [...] absolutely awful – everything we have lost'.

Anna seems to have adopted a form of balanced fatalism that may have kept her stable in the face of considerable adversity. Despite the recurring cancer and bodily changes, as well as anxiety related to recurrence and death (others and own), she views her situation as *simply how things are*. According to Bourdieu (1984), such a perception of life is typical among the lower middle classes, to which Anna belongs in a Norwegian context – one takes life 'as it comes' and one's capital is largely bodily oriented. Overall, Anna's social values speak of acceptance of imperfection, and the family-relational context as a holding environment – it is

everyday life and its events and meetings which really come to the fore in Anna's verbally fluid account. We find a striking contrast between the sober-mindedness in her storytelling and her down-to-earth persona versus the frequently death-defying and self-celebratory heroism characteristic of Americanised cancer previvor and survivor discourses.

*Bente - Generation 2 (50+ years)*

Bente is around 20 years younger than Anna and was diagnosed with invasive cancer in one breast and precancerous cells in the other through annual routine BRCA screening. She was subsequently advised to have both breasts removed, which coincided with her own wishes at the time of diagnosis. Bente's mother died from gynaecological cancer before the BRCA gene mutations were discovered. Bente explains her situation, as follows:

I have been contributing to cancer research since I was 20 or thereabouts, I've been attending regular check-ups because...this has been something we've been worrying about. It's ovarian cancer that's hereditary in our family, so I had my ovaries removed a couple of years ago and we were hoping that we would be spared breast cancer, that it wasn't in our family, but we didn't know anything for sure, for there have been no survivors. So it was in cooperation with medical expertise and with good follow-up that we...although previously I wouldn't necessarily have had [have wanted to have?] my breasts removed. I'm regretting that now, of course. But that was the decision made at the time... Which is why I am now menopausal. Because when I got breast cancer I had to stop taking the hormone tablets [oestrogen supplement] straight away, because they are a trigger. And so I went straight into menopause from one day to the next. It's been quite a party.

This situation is probably typical of the period before the BRCA gene mutations were identified, although as she puts it, they did have 'an inkling' that something was going on in their family, and indeed none of her family members had survived their cancers. Bente's history tells us that it is possible to slip through the safety net put in place to protect individuals with gene mutations. We have no information as to why she was advised to have her ovaries removed prophylactically but not her breasts. In Bente's words, 'that was the decision made at the time', but by whom and on what basis? Did the genetic advisors or clinicians give insufficient advice? Were they perhaps reluctant to suggest that a young woman should remove both breasts, such prominent reminders of embodied femininity, unlike ovaries, which remain unseen whether they are there or not? Did Bente's focus on ovarian

cancer risk, related to her mother's death, cause her to overlook the increased risk of breast cancer?

Bente describes receiving the breast cancer diagnosis, the surgical decision-making processes and the waiting time in the lead-up to surgery as follows:

[When] I was going in to the doctor's surgery there was a nurse who called me in and she told me that she would be accompanying me during the consultation, so I realised straight away that there would be bad news. And it was cancer in the one breast and precancerous cells in the other and then...and then I was given the choice...

Well, they wanted to remove both breasts anyway, there was...there is no breast conservative option when you're in the group that I'm in. So, the decision was made that they should go. And then there were different types of treatment, and I could have the prosthesis put in at the same time, during the operation. [...] And then they phoned a week later and said it wouldn't work out after all. So [because] we have a history of very aggressive cancer, and I never knew what it was I had, nobody had said anything about it and...so I...no-one knows when it'll spread, so I didn't dare wait for a week [to have breasts removed and reconstructed in the same procedure]...

I think I would never have forgiven myself if I chose to wait...to be vain and hang on for a week and...you know, what might happen in a week. And *it was just as if I was walking around with a pair of atomic bombs*, like... [...] So I desperately needed to get rid of them really fast, and I've been really anxious that it would be as aggressive as what my mum had, and of course it was. There was much more cancer than what they had thought. It turned out there was cancer in both breasts and the one that was precancerous turned out to be cancerous as well, as much as 4 cm in diameter. And that was in a single year. There was nothing on the previous mammogram only a year previous. And then there was that much in only a year. I thought that was really scary.

Bente's story illustrates an almost obscure aspect of breast cancer treatment experience: the sheer absurdity of being invited to consider choices relating to aesthetics in the midst of receiving a truly life-threatening cancer diagnosis and therefore being faced with deeply existential issues. Bente had to confront the need for demanding surgical and oncologic treatments to survive whilst at the same time being asked to consider various plastic surgery options that would renormalise her feminine appearance. The lived impact of this medical mixing of curative and plastic surgery at a vulnerable stage in the treatment trajectory, when some patients feel in a state of shock and disbelief, is a relatively new topic (Greco 2015; Gripsrud et al. 2015). Bente's immensely threatening fear of a fast-growing cancer was greater than her need for immediate reconstruction. The fact that she could not bear to wait an extra week for the plastic surgery she initially wanted is evidence of the strong sense of

perceived danger and death anxiety brought on by knowledge of the family's history of fast-growing, aggressive cancers. Bente's story shows how the fear of becoming the culprit of her own misfortune was a significant factor in her surgical treatment choice. In this context, we would like to point out how such powerful emotions can affect patient involvement and decision-making. Choice presented to breast cancer patients in relation to oncologic or plastic surgery may appear irrelevant, if they are not also perceived by the individual, according to her own logic and emotions, to be safe.

Another interesting element in the narrative is how the breasts are perceived as something potentially dangerous and explosive after the cancer diagnosis. Bente refers to her breasts as 'atomic bombs'. It is now well-known how war metaphors are used in both medical jargon and in descriptions of individual illness experiences (Jain 2013; Sontag 1977). Bente's description, very powerful emotionally as she conveyed the overwhelming threat of carrying atomic destruction on her person, suggests how the personal is also produced in an interaction between heavy cultural chains of meaning within which cancer is associated as a superior and devastating disease gestalt: the 'emperor of all maladies' (Mukherjee 2010).

Bente also talks about her daughter, who is in her early teens, and feels a strong sense of guilt that she has brought gene mutations and cancer into her life when her daughter is just about to start becoming a woman. This relational burden of *having knowledge* shows that gene testing can also be experienced as a loss of innocence. The expression *families in waiting* seem to us a more apt description of gene testing's triple effect. Genetic technoscience, which ideally represents a well-meaning biomedical promise of safety and prevention of death and suffering, may also introduce or reinforce anxiety and insecurity, as well as emotionally difficult dilemmas and choices between generations.

#### *Cecilie - Generation 3 (30+)*

So I started thinking that ok, if I am going to have kids – then we'll have to start planning for it now. You can have kids even if you don't have...have your breast reconstructed, like. But

then I was only allowed to think it over for less than a month before I had no choice at all. So that was it, really.

Cecilie is a young adult who was tested for gene mutations at a time when knowledge of BRCA had been available for almost two decades - she knew, since only a short time ago, that she was a BRCA gene mutation carrier. She had just started to consider whether to have her breasts removed prophylactically when she found a lump in her breast:

It started with my sister being gene tested 5 years ago, to see if she had the gene. And then I sort of...no, no I have no need to know in my 20s. No I...and besides it was all like no, then you won't get insurance, and you won't get this or that... Like, there was so much...no, it's not... I have no need to know this or that or the other. But once you're in your thirties you sort of have to take a bit of responsibility and perhaps...it may be better to be checked over and join the screening programmes and that sort of thing. So then I thought that oh well, I had better go in and talk to them. So then they ran the test and I had the gene. And then they recommend...they recommend that I should really have everything removed...

I've never been too fussed about getting married and having kids and all that. I've been working and I got myself an education and that's the path I've taken. I've basically been thinking that it will happen when it happens. And then...so I suppose we got to talk it through a little. And he knows that I have never been totally into having kids. It's not something we've been focusing on. But then I managed to drag out of him that yes, he would actually really like to have children. Eventually, like. And I said that well, then we need to consider what and how. But...yeah, we never got any further down that road before everything just started happening... I noticed something. And then I asked them... 'Cause I hadn't got myself onto any routine checks or anything like that. So I asked if I should wait until the next screening or how it all works. No, that might take a long time, so just ring your GP and then I saw him and I was referred for a check-up. So that was it... Then they proposed this plan which was to...remove the one breast and reconstruct the other. And I was in total agreement that that was really the most sensible thing to do.

Like Bente, Cecilie had a number of serious issues to consider simultaneously – whether to treat the cancerous breast curatively, remove the other breast preventively and whether to go for reconstruction or not. Cecilie's story also illustrates how knowledge generated by gene testing introduces a series of difficult questions and choices. She associates her own decision-making process relating to gene testing with becoming more mature and responsible, while preventive surgery on breasts and ovaries is closely associated with the question of whether she and her partner want children. Her knowledge of hereditary breast cancer in the family, especially the loss of her mother while she was a teenager, meant that she felt a need to plan. At the same time, she talks of *not* having been too preoccupied with having children; instead,

she had wanted to realise her own potential and was contented with this until she was tested. She received her breast cancer diagnosis shortly after starting to consider risk-preventing surgery; her new genetic knowledge had instigated a discussion with her partner who, as it turned out, wanted children and put her in a dilemma. Seemingly, there was an abrupt end to all talk of starting a family, and ‘everything just started happening’, as the cancer appeared palpably in her breast. Cecilie’s story tells of how quickly and unpredictably ‘being at risk’ turns into a ‘risk realized’ in cancer. Importantly, her case reveals how MRI screening per se can never prevent BRCA mutation carriers from developing breast cancer: at best it can only provide a once a year assertion that they didn’t get breast cancer in the year that passed by. Moreover, breast cancers among BRCA mutation carriers tend to produce rapid growing subtypes (Larsen et al. 2014) and may therefore present as palpable tumours between two MR-examinations, as Cecilie experienced. In this respect, for her, the breast cancer diagnosis was an unexpected watershed moment; she went from feeling in control of her life and destiny to a sense of an uncertain future with regard to health and reproduction: even if she kept her ovaries, the adjuvant oncological treatment would prevent her from conceiving for many years after the diagnosis.

## **Discussion**

In the introduction, we raised questions about the advancement of gene technology in a Norwegian context. We aimed to highlight the ways in which knowledge about breast cancer gene mutations shape the subjectivities of the individuals who are left to deal with the potential consequences, practically, aesthetically, emotionally, physically, existentially, and relationally. We also asked how sociocultural factors and identity types that are potentially specific to Norway could intertwine with these dimensions. There are no simple answers to these problems. In fact, there are numerous dimensions to the perceived risk of breast cancer, all forming part of the tapestry in which the diverse threads of scientific ideas, clinical

practice, technological possibilities, forms of treatment and sociohistorical, familial and personal perceptions of risk and safety, fear and hope come to interlock with each other. Earlier critics of gene testing argued that its proliferation leads to a pathologisation of the healthy population. Increasing knowledge about people's genetic material and risk prevention may lead to the formation of new patient groups, as well as a bias in the distribution of public health services caused by a privileging of resourceful people who actively seek to prevent known disease by whatever means available. This may have negative consequences for less resourceful patients who are less determined agents in their own survival and may be prevented from access to knowledge and help in the system. One study showed that the 'cultural health capital' correlated with the probability of taking advantage of mammography screening is a resource acquired early in life (Missinne et al. 2014). We do not know the extent to which such sociocultural factors influence Norwegians' behaviour with respect to genetic testing, but we suspect that similar cumulative mechanisms also exist in the Nordic welfare models. That being said, there is little doubt that medical innovations, including genetic testing, have broadly contributed to significant health improvements. According to Rose (2001), like other biomedicalisation phenomena, gene testing is not just an unavoidable aspect of modern society but also *the knowledge that makes us what we are* – that is, technoscience and medicine are what provide us with our bio-identities. This may be what we see demonstrated by the women interviewed: Although the absence of breasts is worrying to them, it does not mean that their sense of identity has been totally disrupted. This is particularly clear in Anna's story, but neither Bente nor Cecilie show any sign of a 'fundamental deficiency', despite some feelings of disgust or sadness. Instead they show signs of a more pragmatic or stoic coping: Perhaps the experience of loss of both breasts has been balanced against the emotionally overwhelming weight of intergenerational traumas related to early death from cancer. This would be consistent with the clinical impression after years of

experience working with this BRCA patient group, and witnessing how some women exude visible relief as they experience themselves transitioning from ‘patient in waiting’ to becoming a ‘previvor’. Furthermore, this may nuance a number of Norwegian and international perceptions of breast cancer survivors and BRCA previvors in which the breast amputee is expected to renormalize femininity as soon as possible, primarily through reconstructive surgery – another medicalising solution to ‘solve’ complex and embodied breast loss and identity change.

The increased prevalence of preventive surgery for women with mutant breast cancer genes has been influenced by developments in plastic surgery, which now offers immediate prosthesis replacement of a lost breast contour in mastectomy. We assume that health care personnel subsequently have become more at ease with recommending bilateral removal of healthy breasts due to the promise of aesthetic replacement. Thus, the biomedicalisation discourse associated with hereditary breast cancer can also be seen to incorporate a traditional gendered discourse with an unexpected twist: While women with a gene mutation are expected to take responsibility for having their presumptively ‘diseased flesh’ removed, as previvors they wish for the possibility to, or are expected socially to, retain the contours of an apparently visibly intact femininity – becoming a non-reminder of genetic cancer stigma. Thus, they can be seen to pass as ordinary women in the public, apparently, to others, unmarked by their attempts to evade a deadly genetic inheritance. These developments in surgical techniques are likely to have coincided with the ‘Angelina Jolie effect’ since it's likely that women who are more appearance invested (Fingeret et al. 2013) especially younger women in the target group of 33-35 years old, change from being a ‘patient in waiting’ to becoming a complying ‘patient on the waiting list’ when prophylactic mastectomy can be combined with immediate reconstruction. A surgeon’s fantasy may be for every BRCA-patient to become an ‘Angelina Jolie’ in their hands’ making, whilst simultaneously being

able to prevent women from following our three informants' fates. To prevent breast cancer from occurring in younger women (i.e. less than 33 years), future guidelines must re-assess the issue through a vigorous debate on the tradeoffs between benefits of avoiding breast cancer (i.e. to avert the risk of an early death) and the fact their sexual bodies will be made to testify to their genetic cancer risk for the rest of their lives.

The surgical complication rates associated with the immediate reconstruction procedure is one of the highest in plastic surgery, with an overall adverse event frequency of 30- 49%, including minor wound healing problems and major events like nipple necrosis and loss of the prosthesis (Lostumbo et al. 2010). Taking such a high risk of complications into account, we should also recognize risk reduction mastectomy *without* reconstruction as a viable alternative, and recognize that there are other ways to adapt to embodied loss than aesthetic surgical solutions. The "Flat & Fabulous" initiative and our Norwegian newspaper previvor story are illustrative examples of a 'different' way to approach life and identity after surgical risk reduction.

As indicated above, being a breast amputee does not necessarily eliminate the feeling of being at risk; in the Norwegian media representation, a flat chest was seen to represent safety because it facilitated an increased possibility for self-monitoring. Still, the fact that all the women with BRCA-mutations analysed in this paper considered their breasts to be of less significance than what emerges from the American hegemonic discourses on BRCA and breast cancer suggests that the breasts', as visual signifiers of femininity and sexuality, have a somewhat modified status to Norwegian women. This may be associated with social egalitarianism, which values a working body and agricultural traditions involving familiarity with bodily processes, corporality and reproduction. For whatever reason, the women interviewed seemed so deeply engrossed with their rationalisations of treatment/disease/risk/survival that they conveyed a sense of having had quite enough of their

breasts. Perhaps their knowledge about the gene mutations has contributed to a more meaningful separation process (Solheim 1998), where the sacrifice required (loss of breasts, ovaries) may be symbolised as a liberating elimination of a predetermined perilous threat. The atomic bombs can thus become safely defused.

Despite clear parallels between Anna, Bente and Cecilie, some differences in their perspectives are also interesting. This especially goes for Anna versus Bente and Cecilie. Anna grew up in a time without access to gene testing; she did not face the challenge of taking on a *previvor* role until she was middle-aged. After contracting breast cancer in the 1990s, she was encouraged to have her ovaries removed but not her breasts (Møller et al., 1999). She is therefore both a double *survivor* of breast cancer and a *previvor* of ovarian cancer. Anna's story presents an interesting paradox: The individual patient's experience of getting cancer does not necessarily coincide with the cultural and medical production of disease severity in this diagnostic group (she felt well and healthy throughout). We consider that the situation may be different for women of a younger generation. Currently, in developed countries, citizens are presented with knowledge of the gene *before* they act based on statistical calculations as if this form of information tells us as a matter of fact that we *will* become ill. However, as we have demonstrated, risk statistics operate with some noticeably changing margins and genetic mutations may behave differently in different people, putting a heavy question mark over such forms of calculated determinism.

Angelina Jolie Pitt and the American FORCE organisation share the objective of wishing to empower women through knowledge of genetic predispositions for breast cancer. This objective coincides with a global focus on empowerment in a health care and policy context. The empowerment discourse may easily be reinforced by the war metaphors associated with cancer, highlighting the role of the defiant hero (agency in illness), and marginalizing the helpless victim (destiny in illness). Yet, we have found little evidence of

heroic empowerment or battle narratives in our Norwegian data (although breasts as bombs are mentioned).

In concluding this paper, we wish to address the question of whether the *empowerment* ideal, which continues to be advocated through various health, BRCA and breast cancer discourses, reinforces the idealistic but simplified notion of the responsible patient: resourceful enough to seek out medical expertise and gain sufficient knowledge, on which to base informed decisions, thereby reducing the future risk of developing disease (Clarke et al., 2010). Anna and Bente remind us that this ideal is at odds with a different reality. They were both responsible patients: dutifully participating in the screening programme for BRCA carriers for a number of years. They both had their ovaries removed prophylactically but retained their breasts – with dramatic consequences, as we have learned – as the risk of developing cancer for the mutation carriers tends to accelerate and not decrease with age. We will never know why things turned out the way they did because the decision-making processes associated with genetic testing and preventive interventions tend to inhabit the borderlands between health care professionals, patients and families, mediated by GPs, genetic advisors, and a range of specialized medical practitioners (oncologists, breast surgeons, and plastic surgeons). A possible blind spot in the annual MRI screening programme in this local health trust, is that its participants were not simultaneously, whilst ‘in the system’, presented with the option of speaking to a consultant about preventive treatment options, as part of what could have been an on-going longitudinal decision-making process. Thus, based on Anna’s and Bente’s stories, we find there is much to suggest that they fell between the cracks locally while genetic technoscience was still in its infancy, globally. In this respect, Cecilie’s illness trajectory represents cutting edge standards of care: she is young and recently sought out testing and was thus identified as at risk by the health care system, but this was not soon enough to be able to protect her from cancer. It is our view that these

BRCA-cancer-narratives leave us with a paradox: all three interviewees received knowledge about their gene mutations, but none were prevented from developing breast cancer. Bente and Anna were advised to remove their ovaries prophylactic, but not their breasts, whereas Cecilie, who got the BRCA information more recent, was recommended to remove both breasts and ovaries. The sense of safety that gene testing and its associated medical solutions allegedly promise to provide proved illusory for Anna and Bente. Although BRCA-testing offers the potential for protection from adverse DNA-heritage, administered through possibilities for self-monitoring and self-management of the body, the feeling of ‘being in good health’, as our findings show, has hardly been reinforced by the emergence of gene technology.

### THANKS

We wish to thank the three women who contributed their illness stories to the ‘I am not the same’-study. Stavanger Breast Cancer Research Group at Stavanger University Hospital (SUS) approved use of data from the above study. Funding for this research was partly provided by Folke Hermansen Cancer Research Foundation and Inge Steensland Foundation, Stavanger, Norway. We are grateful for the assistance of Senior Consultant/researcher Anne Irene Hagen at St Olav’s Hospital in identifying the year that predictive BRCA gene testing commenced in Norway, and Hildegunn Høberg-Vetti at Haukeland University Hospital for up-to-date information about hereditary breast cancer prevalence in Norway. We also wish to thank Head of Section at the Department of Breast and Endocrine Surgery at SUS, Tone Hoel Lende MD, for her contributions on the clinical context for BRCA counselling and treatment during an early discussion of our topic in 2015. Pål Krøger MD, Head of the Department of Plastic Surgery at SUS, provided reflections on clinical experience with immediate breast reconstruction.

### References

- Boston Health Book Collective. 1971. *Our Bodies Ourselves* Boston Touchstone.
- Bourdieu, P. 1984. *Distinction. A Social Critique of the Judgement of Taste*. . London Routledge
- Cancer Registry of Norway. 2014. Cancer in Norway 2013: Cancer incidence, mortality, survival and prevalence in Norway. Oslo
- Carel, H. 2013. *Illness* Durham ACUMEN
- Chen, S., and G. Parmigiani. 2007. Meta-analysis of BRCA1 and BRCA2 penetrance. *J Clin Oncol* 25 (11):1329-1333. doi:10.1200/JCO.2006.09.1066.
- Clarke, A.E., L. Mamo, J.R. Fosket, J.R. Fishman, and J.K. Shim. 2010. *Biomedicalization: Technoscience, health and illness in the U.S.* Durham Duke University Press.
- Dekeuwer, C., and S. Bateman. 2013. Much more than a gene: hereditary breast and ovarian cancer, reproductive choices and family life. *Med Health Care Philos* 16 (2):231-244. doi:10.1007/s11019-011-9361-9.

- DeShazer, C. 2013. *Mammographies: The cultural discourses of breast cancer narratives*. Ann Arbor University of Michigan Press.
- Dommerud, T. , and J Westerveld. 2014. Valgte å fjerne brystene, livmor og eggstokkene. [http://www.aftenposten.no/nyheter/iriks/Valgte-a-fjerne-brystene -livmor-og-eggstokkene-7604178.html](http://www.aftenposten.no/nyheter/iriks/Valgte-a-fjerne-brystene-livmor-og-eggstokkene-7604178.html) Accessed.
- New York Times 2015, February 9th A never-ending genetic quest: Mary-Claire King's pioneering gene work, from breast cancer to human rights.
- Ehn, B., J. Fykman, and O. Löfgren. 1993. *Försvenskningen av Sverige. Det nationellas förvandlingar*. Stockholm: Natur og kultur.
- Evans, D. G., J. Wisely, T. Clancy, F. Laloo, M. Wilson, R. Johnson, J. Duncan, L. Barr, A. Gandhi, and A. Howell. 2015. Longer term effects of the Angelina Jolie effect: increased risk-reducing mastectomy rates in BRCA carriers and other high-risk women. *Breast Cancer Research* 17.
- Fingeret, M. C., S. W. Nipomnick, M. A. Crosby, and G. P. Reece. 2013. Developing a theoretical framework to illustrate associations among patient satisfaction, body image and quality of life for women undergoing breast reconstruction. *Cancer Treatment Reviews* 39 (6):673-681.
- Frank, A. W. 2013. *The Wounded Storyteller; Body, Illness and Ethics*. Second Edition. Aufl. Chicago/London: The University of Chicago Press.
- Gele, A. A., and I. Harslof. 2010. Types of social capital resources and self-rated health among the Norwegian adult population. *International Journal for Equity in Health* 9. doi:Artn 8 Doi 10.1186/1475-9276-9-8.
- Greco, C. 2015. Shining a light on the grey zones of gender construction: breast surgery in France and Italy. *Journal of Gender Studies* 24 (6).
- Gripsrud, B. . 2008. The cultural history of the breast. In *A cultural encyclopedia of the body*, ed. V. Pitts, pp. 31–44. Westport Greenwood Publishing.
- Gripsrud, B. H, K. J Brassil, B Summers, H. Soiland, S Kronowitz, and K Lode. 2015. Capturing the Experience: Reflections of Women With Breast Cancer Engaged in an Expressive Writing Intervention. *Cancer Nurs*. doi:10.1097/NCC.0000000000000300.
- Gripsrud, B. H. , H. Soiland, and K. Lode. 2014. Ekspressiv skrivning som egenerapeutisk verktøy ett år etter brystkreftdiagnosen – resultater fra en norsk pilotstudie *Nordisk Tidsskrift for Helseforskning* 2:45-61.
- Gullestad, M. 2002. Invisible fences: Egalitarianism, nationalism and racism. *Journal of the Royal Anthropological Institute* 8 (1):45-63. doi:Doi 10.1111/1467-9655.00098.
- Hagen, A. I., S. Tretli, L. Maehle, J. Apold, N. Veda, and P. Moller. 2009. Survival in Norwegian BRCA1 mutation carriers with breast cancer. *Hered Cancer Clin Pract* 7 (1):7. doi:10.1186/1897-4287-7-7.
- Heemskerk-Gerritsen, B. A., M. B. Menke-Pluijmers, A. Jager, M. M. Tilanus-Linthorst, L. B. Koppert, I. M. Obdeijn, C. H. van Deurzen, J. M. Collee, C. Seynaeve, and M. J. Hooning. 2013. Substantial breast cancer risk reduction and potential survival benefit after bilateral mastectomy when compared with surveillance in healthy BRCA1 and BRCA2 mutation carriers: a prospective analysis. *Ann Oncol* 24 (8):2029-2035. doi:10.1093/annonc/mdt134.
- Henderson, L., and J. Kitzinger. 1999. The human drama of genetics: "Hard" and "soft" media representations of inherited breast cancer. *Sociology of Health & Illness* 21:560–578.
- Hoberg-Vetti, H., C. Bjorvatn, B. E. Fiane, T. Aas, K. Woie, H. Espelid, T. Rusken et al. 2016. BRCA1/2 testing in newly diagnosed breast and ovarian cancer patients without prior genetic counselling: the DNA-BONus study. *Eur J Hum Genet* 24 (6):881-888. doi:10.1038/ejhg.2015.196.
- Høberg-Vetti, H. . 2015. Gentesting for arvelig brystkreft <http://onknytt.no/gentesting-for-arvelig-kreft/> Accessed.
- Jain, S. L. 2013. *How Cancer Becomes Us*. Berkeley, CA: University of California Press.
- Jakobsen, S. E. . 2014. Angelina Jolie har fått norske kvinner til å genteste seg: Etter at Jolie fortalte at hun hadde fjernet begge brystene i 2013, strømmer fortsatt norske kvinner til sykehusene for å bli testet for arvelig brystkreft. .

- <http://www.hegnar.no/Nyheter/Livsstil/2015/08/Angelina-Jolie-effekten-paavirker-norske-kvinner>. Accessed.
- New York Times. 2015, March 24th. Angelina Jolie Pitt: Diary of a surgery.
- Jolie Pitt, A. . 2013. May 14th. My medical choice. New York Times.  
<http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html> Accessed.
- Juvet, L. K. , and I. N. Norderhaug. 2008. Gentester for brystkreft og eggstokkreft: Norwegian Knowledge Centre for the Health Services.
- Kitzinger, J. 2007. Framing and Frame Analysis. In *Media studies key issues and debates*, ed. E. Deveorux. London: Sage
- Klawiter, M. 2004. Breast cancer in two regimes: the impact of social movements on illness experience. *Sociol Health Illn* 26 (6):845-874. doi:10.1111/j.0141-9889.2004.00421.x.
- Kleinman, A. 1988. *The Illness Narratives. Suffering, Healing & the Human Condition*. New York: Basic Books.
- Kristvik, E. 2012. The significance of presence. Personal experience and research among incurable cancer patients. *MEDISCHE ANTROPOLOGIE* 24 (1).
- Lagnado, L. 2015 The double mastectomy rebellion – Defying doctors, more women with breast cancer choose double mastectomies. <http://www.wsj.com/articles/defying-doctors-more-women-with-breast-cancer-choose-double-mastectomies-1436545322> Accessed.
- Larsen, M. J., M. Thomassen, A. M. Gerdes, and T. A. Kruse. 2014. Hereditary breast cancer: clinical, pathological and molecular characteristics. *Breast Cancer (Auckl)* 8:145-155. doi:10.4137/BCBCR.S18715.
- Lindelöf, K.S. 2015. Lady Långdistans, Ladylufsen and Kvinnor Kan: Ethnological Perspectives on the Rise of Women-Only Sports Races in Sweden. *Ethnologia Scandinavica* 45:140-157.
- Locock, L., S. Nettleton, S. Kirkpatrick, S. Ryan, and S. Ziebland. 2016. 'I knew before I was told': Breaches, cues and clues in the diagnostic assemblage. *Soc Sci Med* 154:85-92. doi:10.1016/j.socscimed.2016.02.037.
- Lostumbo, L., N. E. Carbine, and J. Wallace. 2010. Prophylactic mastectomy for the prevention of breast cancer. *Cochrane Database Syst Rev* (11):CD002748. doi:10.1002/14651858.CD002748.pub3.
- Lynch, H. T., E. Silva, C. Snyder, and J. F. Lynch. 2008. Hereditary breast cancer: part I. Diagnosing hereditary breast cancer syndromes. *Breast J* 14 (1):3-13. doi:10.1111/j.1524-4741.2007.00515.x.
- Missinne, S., K. Neels, and P. Bracke. 2014. Reconsidering inequalities in preventive health care: an application of cultural health capital theory and the life-course perspective to the take-up of mammography screening. *Sociol Health Illn* 36 (8):1259-1275. doi:10.1111/1467-9566.12169.
- Mukherjee, S. 2010. *The Emperor of All Maladies: A Biography of Cancer*. New York, NY: Scribner.
- Møller, P., A. I. Hagen, J. Apold, L. Maehle, N. Clark, B. Fiane, K. Lovslett, E. Hovig, and A. Vabo. 2007. Genetic epidemiology of BRCA mutations - family history detects less than 50% of the mutation carriers. *European Journal of Cancer* 43 (11):1713-1717. doi:10.1016/j.ejca.2007.04.023.
- Møller, P., A. Stormorken, C. Jonsrud, M. M. Holmen, A. I. Hagen, N. Clark, A. Vabo, P. Sun, S. A. Narod, and L. Maehle. 2013. Survival of patients with BRCA1-associated breast cancer diagnosed in an MRI-based surveillance program. *Breast Cancer Research and Treatment* 139 (1):155-161. doi:10.1007/s10549-013-2540-z.
- National Breast Cancer Group. 2016. Nasjonalt handlingsprogram med retningslinjer for diagnostikk, behandling og oppfølging av pasienter med brystkreft Oslo Helsedirektoratet
- Normannsvik, E. . 2016. Brystkreft: Cancer mammae <https://kreftforeningen.no/om-kreft/kreftformer/brystkreft/> Accessed.
- Norwegian Directorate of Health. 2008. Gentesting ved påvist bryst-eller eggstokkreft og ved vurdering av forebyggende fjerning av eggstokkene. Rapport fra en arbeidsgruppe nedsatt av Helsedirektoratet Oslo
- Rose, N. . 2001. The Politics of Life Itself. *Theory, Culture & Society* 18 (6):1-30.

- Rose, N. . 2007. *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* Princeton and Oxford Princeton University Press
- Sekse, R. J., M. Raheim, G. Blaka, and E. Gjengedal. 2012. Living through gynaecological cancer: three typologies. *Journal of Clinical Nursing* 21 (17-18):2626-2635. doi:10.1111/j.1365-2702.2011.04028.x.
- Skytte, A. B., D. Cruger, M. Gerster, A. V. Laenkholm, C. Lang, K. Brondum-Nielsen, M. K. Andersen, L. Sunde, S. Kolvraa, and A. M. Gerdes. 2011. Breast cancer after bilateral risk-reducing mastectomy. *Clin Genet* 79 (5):431-437. doi:10.1111/j.1399-0004.2010.01604.x.
- Slagstad, R. 1998. *De nasjonale strateger*. Oslo: Pax Forlag AS.
- Solbrække, K.N., and G. Lorem. 2016. Breast-cancer-ization explored: Social experiences of gynecological cancer in a Norwegian context *Sociology of Health & Illness* In print. .
- Solheim, J. . 1998. *Den åpne kroppen; om kjønnsymbolikk i moderne kultur* Oslo Pax Forlag
- Sontag, S. . 1977. *Illness as metaphor*
- Svenaesus, F. . 2013. *Homo patologicus: Medicinska diagnoser i vår tid*. Stockholm: Tankekraft.
- Theissen, S. 2015. On Medicine In *The Angelina Jolie effect*
- Thue, K. 2015. Angelina Jolie-effekten påvirker norske kvinner.  
<http://www.hegner.no/Nyheter/Livsstil/2015/08/Angelina-Jolie-effekten-paavirker-norske-kvinner>. Accessed.
- Timmermans, S., and M. Buchbinder. 2010. Patients-in-Waiting. *Journal of Health and Social Behavior* 51 (4):408-423.
- Woodward, K. 2015. *Psychosocial Studies: An Introduction*. London Routledge
- Yalom, M. 1998. *A History of the Breast*. London Pandora.